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LIVING BEYOND GYNECOLOGIC CANCER: QUALITY OF LIFE AND SEXUALITY AMONG CHINESE WOMEN

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Living beyond gynecologic cancer: quality of life and sexuality among Chinese women

By
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A thesis submitted in partial fulfilment of the requirement for the degree of Master of Philosophy

October 2010

Certificate of Originality

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Abstract of thesis entitled:

Living beyond gynecologic cancer: quality of life and sexuality among Chinese women

Submitted by **Ying Chun Zeng**

For the degree of Master of Philosophy *at* The Hong Kong Polytechnic University *in* October 2010

ABSTRACT

Background: Advances in the early detection and treatment of gynecologic malignancies have provided gains in patients' survival time. Better survival rates have driven the paradigm in the life-altering burden of cancer care from a medical illness model to a wellness model, which was concerned with the quality of life as well as the length of survival. Quality of life (QOL) is one of the health outcomes that enable healthcare providers to better address the ongoing concerns of gynecologic cancer survivors.

Objectives: The objectives of this study were (1) to explore the meanings of QOL among Chinese cervical cancer survivors, and the impacts of cervical cancer survivorship on these Chinese women's QOL; (2) to explore the sexuality concerns of Chinese gynecologic cancer survivors; (3) to describe Chinese nurses' attitudes and beliefs with regard to discussing sexuality concerns with gynecologic cancer survivors, to investigate their current practice in addressing gynecologic cancer patients' sexuality concerns, and to explore the possible facilitators or barriers influencing these Chinese nurses' practice.

Methods: This study was divided into 3 stages. Stage 1 was using a qualitative approach to explore QOL issues among Chinese cervical cancer survivors. Based on the first stage's findings, stage 2 of the study adopted a quantitative approach using a sexuality scale to measure the sexuality concerns of Chinese gynecologic cancer survivors. The final stage of this study also adopted a quantitative approach to explore Chinese nurses' attitudes and practice of sexuality care.

Results: A total of 35 Chinese cervical cancer survivors participated in stage 1 of this study. The meanings of QOL perceived by these Chinese women include being free of disease, having a good living standard, having a harmonious family atmosphere, being able to work independently, and having a harmonious sexual life and sexual relationships with partners. The impacts of cervical cancer on Chinese women's QOL include physical and psychological sequelae, family distress, financial burden and disruptions in social function. The result of study stage 1 indicated that sexuality concerns had greatly impacted on the QOL of these women. Therefore, the stage 2 of this study was focused on the sexuality issues of this target population.

Stage 2 of the study recruited 156 Chinese gynecologic cancer survivors from 3 hospitals in China. Study results revealed that the participants (63.9%) were generally positive towards their own body appearance. However, a large percentage (69.3%) of the women reported that cancer had influenced their overall quality of life in terms of sexuality and intimate relationships. Sexual dysfunction was an important concern among these women (62.2%). The rate of sexual inactivity (70.5%) was relatively high. Reasons for sexual inactivity were related to worry about possibly weakening the potency of treatment (46.5%), fear of cancer recurrence (41.1%), and lack of sexual interest (31%). Older age (>50 years old) was associated with the decrease of sexual desire/interest (OR 3.64, CI 1.19-11.16). Women who received radiation therapy suffered from more severe vaginal dryness (OR 2.27, CI 1.10-4.72) and were less sexually active than those who did not have radiation therapy.

Stage 3 of the study recruited a sample of 202 nurses working in Gynecologic Cancer Units from 6 hospitals in China. Study results revealed that the majority of nurses (77.7%) held the attitude that 'sexuality is too private an issue to discuss with patients'. Only 34.2% 'make time to discuss sexual concerns with patients'. Regression analysis revealed that nurse' marital status and hospital type (these two variables accounting for 23.1% of the variance) in which they were working influenced their practice in sexuality care. Nurses' conservative attitudes toward sexuality, their prejudices regarding gynecological cancer, the lack of availability of private environment, the lack of sexuality care training, and the failure to include sexuality care in routine nursing care (these variables accounting for 31.1% of the

variance), were found to be factors that significantly influence sexual care in nursing practice.

Conclusions: The study stage 1 demonstrated the importance of considering the impact of cervical cancer survivorship on Chinese women's QOL. The study stage 2 indicated that Chinese gynecologic cancer survivors suffered from various sexuality concerns. Addressing sexuality concerns of this target population should offer relevant psychosexual education interventions to dispel these women's related fears and misconceptions. The study stage 3 revealed that Chinese nurses assumed sexuality concerns being not a priority issue for gynecologic cancer patients, and were less likely to make time to discuss sexuality issues with patients. There is a need to increase Chinese nurses' awareness of their roles and the need to equip themselves with relevant skills in providing sexuality care for patients.

Publications arising from the MPhil thesis

1. **Zeng YC**, Ching SSY & Loke AY (2011) Quality of life in cervical cancer survivors: a review of literature and directions for future research. *Oncology Nursing Forum*, 38 (2): E107-E117.
2. **Zeng YC**, Ching SSY & Loke AY (2010) Quality of life measurement in women with cervical cancer: implications for Chinese cervical cancer survivors. *Health and Quality of Life Outcomes*, 8:30doi:10.1186/1477-7525-8-30. Available at: http://www.hqlo.com/content/8/1/30
3. **Zeng YC**, Li DM & Loke AY. Life after cervical cancer: quality of life among Chinese women. *Nursing and Health Science*, (1st revision under review).
4. **Zeng YC**, Li QP, Li XF & Loke AY. Sexuality concerns among Chinese women after gynecologic cancer. *The Journal of Sexual Medicine*, (under review).
5. **Zeng YC**, Liu XY & Loke AY. Addressing sexuality issues of women with gynaecological cancer: Chinese nurses' attitudes, beliefs and practice. *Journal of Advanced Nursing*, (accepted for publication).
6. **Zeng YC,** Li QP, Wang N, Ching SSY & Loke AY (2010) Chinese nurses' attitudes and beliefs toward sexuality care in cancer patients. *Cancer Nursing*, In Press (available on-line).
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International Conference Oral Presentation

1. **Zeng YC** & Loke AY. Addressing sexuality issues of women with gynecological cancer. The 2nd Rotterdam Symposium on Cancer and Sexuality: Controversies in Cancer and Sexual Function. Rotterdam, the Netherlands. (Presented on June 4, 2010)

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Chapter 1

Introduction and the Thesis Outline

1.1 Introduction

Advances in the early detection and treatment of gynecologic cancer have provided gains in patients' survival time. Better survival rates have driven the paradigm in the life-altering burden of cancer care from a medical illness model to a wellness model, which was concerned with the quality of women's lives as well as the length of survival (Wolff, 2007).

While women live longer after being diagnosed with gynecologic cancer, they are also living with its sequelae and have a need for support, so that it is necessary to pay special attention to the impact of cancer and its treatment on quality of life among this target study population. Quality of life (QOL) is one of the health outcomes that enable healthcare providers to better address the ongoing concerns of gynecologic cancer survivors. The concept of quality of life (QOL) is particularly salient for nursing, because nurses are traditionally concerned with the holistic perspective of patients, focusing on their survival as well as their QOL (Ferrans, 2005). In consequence, nurses play important roles in maintaining the QOL of gynecologic cancer survivors.

1.2 Key concepts in this study

1.2.1 Cancer survivors

The term of 'cancer survivors' has been defined by different ways: in medical community, physicians took a 5-year frame to define cancer survivorship. Individuals are considered as survivors if they live five years following the initial diagnosis of cancer without recurrence (Leigh, 1996). According to the American National Cancer Institute Office of Cancer Survivorship (2006), 'cancer survivor' refers to a person lives with cancer from the time of diagnosis through the remaining years of life, including individuals' family members, friends, and caregivers. The trend for most recent research into cancer survivors is focused on those individuals with cancer diagnosis, and begins on the completion of primary treatment or the major aspects of treatment (Feuerstein, 2007). In this thesis, gynecologic cancer survivors were defined as women who have completed their initial cancer treatment.

1.2.2 Quality of life

The concept of quality of life

There are many attempts to define the term of QOL. Dubos (1976) defined QOL as value judgment associating with profound satisfaction from the activities of daily living. Similarly, Szalai (1980) indicated that QOL is a global evaluation of an individual's description of satisfaction with life. Both researchers took QOL as satisfaction of individuals' daily living.

Other definitions of QOL were based on the individual's expectations. Caplan (1984) stated that QOL is concerned with the difference between perceived and actual goals. This means that QOL is viewed as individuals' goals and expectations in their lives. In a similar way, Calman (1987) defined QOL as the difference between the hopes and expectations of the individual and the individual's present experience. Based on individuals' expectations or satisfactions, these definitions of QOL are following with an individual centered paradigm.

The World Health Organization (WHO) (1996) conceptualized the QOL as "an individual's perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, levels of independence, social relationships, and their relationship to salient features of their environment (p354)". Compared with other QOL definitions, the WHO incorporates contextual factors into the interpretation of QOL. The concept of QOL may contain a wide variety of issues including physical and psychological health, social well-being, cultural and socio-ecological issues, and living conditions.

Framework of quality of life

In measuring the perceived QOL of cancer survivors, Ferrell et al. (1997) proposed a model that includes domains of physical, psychological, social, and spiritual well-being. The four QOL domains are defined as follow:

1) Physical well-being is the control or relief of symptoms and the maintenance of function and independence
2) Psychological well-being is the attempt to maintain a sense of control in the face

of life threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown as well as positive life changes

3) Social well-being is the effort to deal with the impact of cancer on individuals, their roles, and relationships
4) Spiritual well-being is the ability to maintain hope and derive meaning from the cancer experience which is characterized by uncertainty (Ferrell et al., 1997)

A review of QOL studies dealt specifically with cervical cancer survivors, Vistad et al. (2006) found that the impact of cervical cancer survivorship on QOL mainly includes the physical, psychosocial, and sexual sequelae. This study adapted Ferrell et al.'s QOL model, and added sexual well-being as another important domain of QOL among cervical cancer survivors. As a result, the framework of QOL in this study includes five domains: physical, psychological, social, spiritual and sexual well-being.

Culture and quality of life

As culture may influence all aspects of the expectation of health and illness, so culture is a major determinant of QOL and perceptions of QOL are embedded in culture beliefs about what constitutes health (Padilla & Kagawa-Singer, 2003). QOL studies in Western countries tend to define QOL in relation to being healthy and independent, reclaiming life, psychological well-being or social relationships (e.g. Dow et al., 1999). In Chinese culture, the family relationship and kinship play very important roles in daily life. Personal achievement sometimes gives way to the wellbeing of the extended family, Taoism and traditional medicine focus on good temper and high spirit: good appetite, sleep, and energy are highly regarded in daily life (Wan et al., 2008). Chinese cancer survivors view "normal living", a good working life, happiness, material resources and support from their families as essential indicators of QOL (Yang & Yin, 1999; Molassiotis et al., 2000). Therefore, cultural difference may influence individuals' interpretations of QOL.

1.2.3 Sexuality

The concept of sexuality

'Sexuality' is a multidimensional phenomenon encompassing the following dimensions: sexual activity – not limited to sexual intercourse and including any activity of a sexual (as opposed to purely affectionate) nature from holding hands to sexual intercourse (Byers, 1998); sexual function – the ability to engage in the act of

sex with a response cycle of desire, arousal, lubrication, orgasm and satisfaction (Rice, 2000a, Rosen et al., 2000); body image – pervades individuals' biological being and sense of self (Kozier et al., 2004); role identities – including both gender identity (based on biological make-up such as being male or female) and sexual identity (individuals' preferences for one types of sexual activity to the other) (Kozier et al., 2004); and sexual relationship issues (the way in which people relate to their intimate partners).

Chinese culture and sexuality

Culture has long been recognized as one of the most powerful factors influencing health-related attitudes and beliefs (Spector, 2004). Chinese thought and culture are heavily influenced by the teachings of Confucius (Woo et al., 2009). Based on Confucian philosophy, sexuality is viewed as serving as a purely procreative role in Chinese culture, and discussing sexual issues outside marriage is highly inappropriate (Khoo, 2009). Chinese cultural traditions also emphasize strict moral and social conduct, thus modesty and restrained sexuality are valued (Abraham, 1999). Consequently, Chinese nurses are likely to allow conservative attitudes toward sexuality-related issues to influence their practice.

1.3 Knowledge gaps

While there is a growing body of literature documented QOL and sexuality among gynecologic cancer survivors, these studies mainly conducted in Western culture countries. By virtue of social and cultural difference as discussed previously, study findings from Western culture countries may not be appropriate to generalize to Chinese women. Consequently, relevant studies are needed to conduct among Chinese gynecologic cancer survivors to fill these knowledge gaps.

1.4 Aims of this study

This is a 3-stage study. The aim of this study was to explore the QOL issues among Chinese gynecologic cancer survivors. Based on study findings of stage 1, the aims of next two study stages were to examine sexuality concerns of gynecologic cancer survivors from both patients and nurses' perspectives.

1.5 Significance of this study

This study made contributions to the knowledge base and added insight into the issues of QOL and sexuality concerns among Chinese gynecologic cancer survivors. Equipped with this information, nurses and other healthcare professionals providing service to gynecologic cancer survivors can develop appropriate interventions and supportive care, which would facilitate to promote the QOL and overall survival outcome for this target population.

1.6 The thesis outline

This is a thesis of an academic peruse of the quality of life, with a focus on sexuality, among Chinese gynecologic cancer survivors. The whole thesis consists of four parts and is organized into eight chapters. Part 1 includes two chapters to provide the study background. Part 2 includes one chapter to describe study methods. Part 3 includes three chapters to report study findings. Part 4 includes two chapters to discuss study findings, to make recommendations for nursing education, practice and further nursing research, and to draw conclusion of this study.

Chapter 2

Literature Review

Stage 1 Review of quality of life among cervical cancer survivors

Stage 2 Review of sexuality issues among gynecologic cancer survivors

Stage 3 Review of addressing sexuality issues from nurse perspectives

Stage 1 Review of quality of life among cervical cancer survivors

2.1 Cervical cancer and Quality of life

Cervical cancer is one of the most common types of cancer in developing countries. With nearly 500 000 women developing cervical cancer per year, China's estimated 131 500 new cases constitute 28.8% of the total new cases annually worldwide (China Cancer Database, 2004). Due to widespread screening programs, the majority of cases of cervical cancer are being diagnosed in the earlier stages. Along with new and advanced medical treatment, women with cervical cancer have relatively good 5-year survival rates. The overall 5-year survival rate of all stages of cervical cancer survivors in China has been estimated to be 70.93% (Yin et al., 2004).

Despite better survival rates, cervical cancer survivors may continuously live with sequelae such as long-term and late physical, psychosocial and sexual effects of treatment (Vistad et al., 2006). Quality of life (QOL) assessment among cancer survivors can aid the detection of these late effects and long-term sequelae, which otherwise might be overlooked (Victorson et al., 2007). The findings obtained from QOL assessment may also allow healthcare professionals to understand better the impact of cancer diagnosis and its treatment on survivors' well-being and functioning, and to anticipate what could happened and should be done for future cancer survivors (Fayers & Machin, 2007). Thus, the outcomes of these QOL assessments provide important information on facilitating treatment decisions, and guiding healthcare providers at developing more effective supportive care for cervical cancer survivors.

2.1.1 Quality of life among cervical cancer survivors

Research on cervical cancer survivors has reported various QOL concerns including physical, psychological, social, and sexual aspects. Major physical impacts include permanent consequences for childbearing, as well as menopausal, urological and gastrointestinal symptoms and a high prevalence of fatigue (Korfage et al., 2009). These physical dysfunction and symptoms severely influence women's life quality

(Hodgkinson et al., 2007). Common sequelae disrupt the psychological aspects of life for cervical cancer survivors include uncertainty in the future, loss of fertility, fear of recurrence, distress, anxiety, depression, self-concept changes such as reduced self-confidence, and altered experience as women (Ashing-Giwa et al., 2004; Bradley et al., 2006).

Women may also face disease-specific social sequelae issues such as social stigma and social isolation, linked to social associations between cervical cancer and unsafe sexual practices (Lai et al., 2009). Other social issues affecting life quality include financial difficulties and reduced role functioning, at home, at work and during leisure activities (Molassiotis et al., 2000; Distefano et al., 2008). High rates of sexual morbidity among cervical cancer survivors have also been documented (Lindau et al., 2007). The major sexual and reproductive side-effects of treatments for cervical cancer include reduced sexual desire, lack of arousal and orgasm, diminished lubrication, and reduction in vaginal elasticity and a shortened vaginal cavity, which often inhibit patients' ability to resume satisfactory sexual functioning (Jensen et al., 2003; 2004). In short, altered sexuality and sexual dysfunction may also contribute to negative perceptions of QOL among cervical cancer survivors.

2.1.2 Measurements of quality of life in cervical cancer survivors

A variety of questionnaires have been used to assess QOL in women with cervical cancer. Zeng et al. (2010a) summarized that there were four types of QOL instruments used which were: generic (e.g. Medical Outcome Study: 36-Item Short Form Survey-SF-36) (Distefano et al., 2008), cancer-specific (e.g. European Organization for Research Treatment's QOL cancer-specific questionnaire-EORTC QLQ-C30) (Greimel et al., 2009), cancer site-specific (e.g. Functional Assessment of Cancer Therapy-Cervix-FACT-Cx) (Ashing-Giwa, 2008) and cancer survivors-specific (e.g. Cancer Survivors Unmet Needs-CaSUN) (Hodgkinson et al., 2007). While these instruments vary in length and emphasis, it has been reported that none of them is

comprehensive enough to explore all domains of QOL across the survivorship continuum (Zeng et al., 2010a).

There is an increasing amount of quantitative evidence available on QOL among Chinese cervical cancer survivors in recent years (e.g. Liu et al., 2006; Zhang et al., 2009). However, there is a lack of qualitative insights on the impact of cervical cancer and related treatment on Chinese women's survivorship experience. Thorne (1997) argues that quantitative approaches are of limited use in answering human subjectivity and interpretation. In consequence, this scientific evidence base needs qualitative approaches to explore women's subjective meanings and perceptions of QOL.

Stage 2 Review of sexuality issues among gynecologic cancer survivors

2.2 Gynecologic cancer and sexuality

Issues surrounding sexuality greatly impact quality of life on women with gynecologic cancer (Ratner et al., 2010). Although advances in the early detection and treatment of gynecological malignancies have provided gains in patients' survival (Armstrong, 2002), these gains are often accompanied by elevated rates of sexual morbidity among gynecologic cancer survivors (Barton, 2003; Parkinson & Pratt, 2005). It is increasingly acknowledged that sexuality has been recognized as an integral aspect of quality of life for patients with gynecologic cancer (Juraskova et al., 2003), and that sexuality is a legitimate area of concern in oncology (Mercadante et al., 2010). There is a growing acknowledgement that sexuality concerns of gynecologic cancer survivors are not being adequately addressed by healthcare providers (Park et al., 2009; Stead et al., 2003, 2007).

2.2.1 Sexuality in women with gynecologic cancer

Sexuality refers to an individual's personality and is multifaceted (Gotheridge & Dresner, 2002). Alternations in body image are very common in women with gynecologic cancer (Tabano et al., 2002). A qualitative study highlighted a range of body image changes of women suffered from cervical and endometrial cancer: loss of hair and loss of attractiveness were some of more prominent concerns; they also felt less of a woman and were worried about how they feel sexually (Juraskova et al., 2003).

The diagnosis and treatment of gynecological cancer may also threaten a woman's role identity, sense of femininity, and interpersonal relationships (Stead et al., 2007). A woman who loses her fertility feels herself to be useless, incomplete, disliked, and valueless (Reis et al., 2010). These women may no longer feel whole, with a vital life role. They may lose their roles as giver of life, which is especially important if the woman has been anticipating motherhood (Gotheridge & Dresner, 2002; Reis et al., 2010). The changes in their sexual feelings may also affect the relationship with their partners. Many women found that the changes in their sexual feelings affected the relationship with their partners and cause marital problems (Stead et al., 2007).

One longitudinal research indicates that approximately 50% of women treated for gynecologic cancer have some sexual dysfunction as cancer survivors (Anderson & Lutgendorf, 1997). The estimates of sexual dysfunction for women with gynecologic cancer range from 20% to 100% (Tabano et al., 2002). Depending on the surgical procedure underwent and the cancer type treated, gynecologic cancer survivors may experience significant sexual dysfunction and adverse vaginal changes, such as lack of sexual desire, lack of lubrication, dyspareunia, problems with orgasm, vaginal shortness, problems by completing sexual intercourse, compromising their sexual activity and sexual satisfaction throughout the first two years after radiotherapy (Jensen et al., 2003; 2004). It was found that patients with more advanced cervical

cancer reporting more sexual problems – such as vaginal dryness, dyspareunia, difficulties with sexual arousal – than women underwent surgery for less advanced cervical cancer (Frumovitz et al., 2005).

Studies related to the impact of gynecologic cancer on women's sexuality indicated that the frequency of sexual activity was less than the frequency before the cancer diagnosis in many women (Tabano et al., 2002). About 58% of women who were sexually active before cancer refrained completely from sexual intercourse after the diagnosis (Khoo, 2009). In a longitudinal study, between 33% and 50% of gynecologic cancer survivors reported not resumed sexual activity within a year following treatment (Lutgendorf et al., 2002). A study among Chinese cervical cancer survivors found that 60% Chinese women reported a complete ceasing of sexual activity following a diagnosis of cervical cancer (Liu et al., 2006). In a qualitative study interviewing 35 Chinese cervical cancer survivors (completed their primary cancer treatment more than 1 year), 13 out of 35 informants reported no sexual intercourse since the diagnosis of cervical cancer (Zeng et al., in press-a). Other aspects of sexual behaviors such as kissing and cuddling were affected among gynecologic cancer survivors, although this was usually temporary (Stead et al., 2007).

2.2.2 Measurements of sexuality in women with gynecologic cancer

A review of sexual function measures identified a total of 31 instruments used to assess sexual function among all types of cancer patients (Jeffery et al., 2009). The three sexuality instruments most frequently used among gynecologic cancer patients are the Female Sexual Function Index (FSFI), the Sexual Activity Questionnaire (SAQ), and the Sexual function-Vaginal changes Questionnaire (SVQ) (Jeffery et al., 2009).

The FSFI is a generic scale designed to assess the sexual function of the female population, and originally developed by Rosen et al. (2000). It includes 19 items and

consists of 6 domains: desire, arousal, lubrication, orgasm, satisfaction and pain. The six subscales of FSFI have good discriminant validity as the FSFI is able to discriminate between clinical and nonclinical populations (Rosen et al., 2000). Rosen et al. further reported that the FSFI has excellent internal consistency of reliability (Cronbach's $\alpha > 0.9$ for all subscales) and good test-retest reliability (scores ranged from 0.79-0.88). The advantage of this instrument is that the FSFI can be used to compare sexual function between health women and women with gynecologic cancer or other disease conditions. Due to its briefness, the FSFI was widely used to evaluate the sexuality of women with gynecologic cancer (Schroder et al., 2005; Liu et al., 2008; Levin et al., 2010). Nevertheless, the FSFI is only appropriate for use among women who have some level of sexual activity during the measurement period (Rosen et al., 2000). Other shortcomings are that the FSFI does not include items to measure sexual and vaginal problems specific to gynecologic cancer survivors.

The SAQ was originally developed to investigate the impact of long-term tamoxifen on the sexual functioning of women at high risk of developing breast cancer (Thirlaway et al., 1996). It includes 21-item and consists of 3 parts: hormonal status, reasons of sexual inactiveness, and sexual function. The SAQ is suitable for sexually active and inactive women during the period of measurement. Another advantage of SAQ is able to discriminate the sexual functioning of pre- and post-menopausal women (Thirlaway et al., 1996). The SAQ was also widely applied in the population of gynecologic cancer patients. Carmack Taylor et al. (2004) used the SAQ among 233 ovarian cancer patients, and reported the test-retest reliability by Pearson's correlation coefficient for was ranging from 0.68-1.00 for individual items. The internal consistency of SAQ was 0.81 by Cronbach's α established in a study among 49 ovarian cancer survivors (Wenzel et al., 2002). The disadvantages of the SAQ are its lack of items to assess broader aspect of women's sexuality, and its failure to measure the unique sexuality concerns of gynecologic cancer patients or survivors.

The SVQ is a cancer site-specific scale tailored to measure the sexual function of women with gynecologic cancer. It includes of 27 items and covers the domains of sexual interest, lubrication, orgasm, dyspareunia, vaginal conditions, intimacy, body image, and sexual activity and satisfaction. The content validity was evaluated by interviewing with gynecologic cancer patients and comments from health professionals specialized in gynecologic oncology (Jensen et al., 2004). The construct validity of SVQ was established by principle component analysis: individual items' factor loading were all with an acceptable level (more than 0.5). The internal consistency of all subscales of SVQ was ranging from 0.76-0.83 (Jensen et al., 2004).

Empirical evidence shows the SVQ with a high sensitivity and responsiveness to changes for assessing unique sexual and vaginal problems associated with gynecologic cancer and its treatment (Jensen et al., 2003). The disadvantages of the SVQ include the fact that, for those women who may have been sexual inactive during the measurement period, the SVQ failed to provide underlying reasons, which would be important in guiding healthcare professionals to develop relevant interventions to address this target population's sexuality concerns. In addition, the SVQ includes few items to assess the domain of body image concerns in an in-depth manner. Finally, it lacks items to measure the domain of role and sexual relationship issues. Although these sexuality scales have good reliability and validity among Western women, none of them has been established its reliability and validity among Chinese gynecologic cancer survivors.

In summary, gynecologic cancer survivors confront numerous challenges to their sexuality, including changes in body image, alterations in role identities and sexual relationships, sexual dysfunction, and decreasing or ceasing sexual activity. While there is an increasing body of literature documenting gynecologic cancer survivors' sexuality concerns, few of these studies were conducted in China.

Stage 3 Review of addressing sexuality issues from nurse perspectives

2.3 Nurses' roles in addressing patients' sexuality concerns

Nurses, through their frequent contacts with patients, play an important role in addressing patients' sexuality concerns (Higgins et al., 2006). In recent years, the literature has acknowledged sexuality as a legitimate area of concern for nurses caring for cancer survivors (Rice, 2000b; Higgins et al., 2006; Odey 2009). The American Nurse Association has, since 1974, recognized sexuality as an important aspect of patient care (Nakopoulou et al., 2009). Although most nurses would agree that sexuality assessment of patients is part of holistic care (Haboubi & Lincoln, 2003), for a number of reasons, they do not address patients' sexuality concerns in their nursing care practice (Higgins et al., 2006).

2.3.1 Reluctance of nurses in addressing patients' sexuality concerns

There are various factors causing patients' sexuality concerns to be overlooked by healthcare providers. One of the reasons may be the myths and prejudices that are prevalent among healthcare providers about patients diagnosed with cancers being too ill to be interested in sex or sexual issues (Sunquist & Yee, 2003). Other myths include that gynecologic cancer can infect partners during sexual intercourse, and that sexual activity can worsen a woman's condition and delay her recovery from gynecologic cancer (Molassiotis et al., 2002).

Additionally, nurses may avoid discussing sexuality issues with their patients because they believe that dealing with patients' sexual issues is not within their professional responsibility (Nakopoulou et al., 2009), and they are afraid of offending patients (Katz, 2005). Some nurses and other healthcare professionals feel that they are not adequately prepared with relevant knowledge and skills to discuss sexuality with their patients (Gott et al., 2004; Stilos et al., 2008). Others may believe that their patients do not expect to discuss their sexuality concerns with them (Magnan & Reynolds, 2006).

Since nurses' attitude and beliefs influence their professional practice, it is important to understand these factors when identifying practice surrounding the discussion of sexuality concerns with gynecologic cancer survivors.

2.4 Summary

Numerous quantitative findings show that there is a variety of QOL concerns among cervical cancer survivors, and there is a lack of qualitative insights on the impact of cervical cancer and related treatment on Chinese women's survivorship experience. Sexuality is a universal human experience and a vital component of quality of life (Krebs, 2008; Bancroft, 2009). While there is an increasing body of literature documenting gynecologic cancer survivors' sexuality concerns, few of these studies were conducted in China. Since nurses play an important role in addressing sexuality concerns of patients, it is important to understand their attitude and practices as regards addressing gynecologic cancer survivors' sexuality concerns.

Part 2
Study Methods

Chapter 3

Study Objectives and Methods

3.1 Study objectives

This study originally aimed at exploring the quality of life (QOL) among Chinese cervical cancer survivors. From literature reviews in chapter two, there is a plethora of quantitative evidence documenting various QOL concerns among cervical cancer survivors. Thus, the first stage of this study intended to adopt a qualitative approach to explore the QOL issues among Chinese cervical cancer survivors. Based on the study findings from stage 1, sexuality issues were one of important parts of QOL concerns among Chinese cervical cancer survivors. The second stage of this study focused on exploring the sexuality issues of gynecologic cancer survivors (Due to time limitation and the difficulty in recruiting subjects of cervical cancer survivors, the study population in the second stage was including all types of gynecologic cancer survivors).

As indicated in chapter two, nurses were reluctant and less likely to discuss sexuality issues with patients. Therefore, the final stage of this study set out to examine Chinese nurses' attitudes and practice in providing sexuality care for women with gynecologic cancer.

The objectives of this study were to

1. Explore the meanings of QOL among Chinese survivors of cervical cancer
2. Explore the impacts of cervical cancer survivorship on these Chinese women's QOL
3. To explore the sexuality concerns (body image, role and sexual relationship, sexual activity and sexual function) of Chinese gynecologic cancer survivors
4. To describe Chinese nurses' attitudes and beliefs with regard to the sexuality concerns of women with gynecologic cancer
5. To investigate Chinese nurses' current practice in addressing the sexuality concerns of women with gynecologic cancer
6. To explore the possible facilitators or barriers influencing these Chinese nurses

to provide sexuality care in practice

3.2 Study methods

3.2.1 Study design

A mixed method involving both qualitative inquiry and quantitative approach was employed in this study because of several reasons. Firstly, there was no qualitative study focusing on the QOL among Chinese cervical cancer survivors, although there were several quantitative studies conducted previously among this target study population. Secondly, the use of questionnaires provides a convenient way of investigating women's sexuality concerns. Finally, a mixed method approach could be used to allow for measures of some dimension of the phenomenon under investigation (Morse & Niehaus 2007). In this study, study stage 1 using the qualitative approach identified that sexuality issues were important but being under investigated. Subsequently, study stage 2 was used a quantitative approach to investigate patients' sexuality concerns in an in-depth way. Therefore, a mixed method design offset the weakness of using either qualitative or quantitative research methods.

The first stage of this study was a qualitative study. Written narratives using open-ended questions were adopted to obtain information on Chinese cervical cancer survivors' perceptions of QOL. The second and third stages of this study were correlational quantitative study.

3.2.2 Sample and the study setting

In the first study stage, cervical cancer survivors, defined as individuals alive after initial treatment for cervical cancer, were recruited from a Tumor Hospital in mainland China to explore their perceptions of QOL. Purposive sampling strategy was employed to select participants for this study. The inclusion criteria for the sample were: (1) Chinese women at least 18 years old and with a diagnosis of cervical cancer; (2) completed primary cancer treatment; and (3) currently cancer free (no cancer recurrence or no metastasis). Written narratives were delivered to patients by a nurse

until ‘data saturation’. This is the justification of sample size for this study stage.

In the second study stage, gynecologic cancer survivors, defined as women alive after initial treatment for gynecologic cancer, were recruited from 3 hospitals in mainland China to explore their sexuality concerns. They were recruited from the gynecologic units or gynecologic outpatient departments of these hospitals. The inclusion criteria were: (1) aged 18 years or older, (2) diagnosed with gynecologic cancer for the first time; (3) completed primary cancer treatment; and (4) no known cancer recurrence (i.e. in the state of cancer-free survivors at the time of study).

In the third study stage, since gynecologic cancer patients are treated in both general and oncology hospitals, a convenience sample of nurses from 6 hospitals in China (3 oncology hospitals and 3 general hospitals in mainland China) was recruited to explore these nurses’ attitudes and practice regarding sexuality care. The inclusion criteria were: (1) Chinese nurses working in gynecologic cancer units in the selected oncology or general hospitals; and (2) clinical nurses engaged in the delivery of direct patient care.

The justification of sample size for the second and third study stages was based on two principles: (1) For instrument validation, the sample size based on the item of instruments. In general, 5 to 10 subjects per questionnaire item to generate stable reliability and validity estimates (Hao & Wan, 2000). In the second stage, the sexuality scale has 32 items, so that the minimum total number of subjects requires 160. In the third study stage, the minimum total number of subjects requires 100. (2) In the third study stage, it needs correction analysis to identify nurses’ demographic characteristics with nurses’ sexuality practice scores. Based on previous literatures, with α set at 0.05 and power set at 0.80, a sample size of 132 subjects would be needed to detect statistically significant small correlations (r = 0.25) (Magnan & Reynolds, 2006).

3.2.3 Data collection

Written narratives as means of qualitative data collection

Written narratives were used to collect data in the first study stage. Compared with face-to-face interviews, written narratives have the advantage of putting participants under less interaction pressure (Salander, 2002). Written narratives do not require transcriptions, so this method is less time-consuming and more cost-effective (Hamilton & Bowers, 2006). Other advantages are that written narratives may overcome the barriers of dialects, as people in mainland China typically speak many different kinds of Chinese dialects even within the same province.

The impersonal nature of the written narratives might also help people to express feelings or perceptions that they would not be willing to describe in person in a face-to-face interview (Hunt & McHale, 2007). In particular, when survivors of cervical cancer are asked about sensitive issues such as sexual health, they are more likely to share their perceptions in written form rather than expressing them verbally. However, the disadvantages of written narratives may be the lack of interactions between interviewers and interviewees, and the absence of the spontaneity responses that are obtained in face-to-face interviews (Holloway & Wheeler, 2002).

The question guide for patients

Eligible women were invited to fill in a demographic sheet and some open-end questions (Appendix 1, 2) about their perceptions of QOL. All participants were recruited from the tumor hospital's gynecologic outpatient department. A gynecologic oncologist helped in data collection. Women were asked to return their written narratives to the hospital or to return by mail.

Instruments for the quantitative data collections

In the second study stage, all gynecologic cancer survivors were asked to fill in a demographic sheet and a Sexuality Scale (Appendix 3, 4). The demographic sheet was used to collect gynecologic cancer survivors' demographic and medical information, such as age, education level, employment status, marital status, motherhood, disease stage, types of treatment received, time since completing primary treatment, and types of gynecologic cancer.

The sexuality scale for patients

The sexuality scale consists of two parts. The first is composed of 5 subscales and 32 items: body image (5 items), role and relationship issues (5 items), sexual activity (5 items), sexual function (10 items), and 7 additional items (comparison of sexuality issues between pre-post cancer diagnosis). These 32 items were developed based on relevant literatures and tools (Brown et al., 1990; Jensen et al., 2004; Thirlaway et al., 1996; Wilmoth et al., 2006). The second part includes 15 statements of reasons for sexual inactivity. These statements were developed from SAQ (Thirlaway et al., 1996) and the findings of qualitative interviews with Chinese cervical cancer survivors (Items# 9, 10, 11 &15 were selected from qualitative study findings in stage 1).

Response formats of the sexuality scale

Responses to this sexuality scale are in the Likert scale format (scores ranging from 4 to 1). Higher scores indicate a more negative impact of sexuality. Positively worded items have to be reversely scored. Specifically, responses in the subscale of body image are 4 (definitely agree), 3 (agree), 2 (disagree), and 1 (definitely disagree). Higher scores on the subscale reflect more negative feelings toward body image. Response in the subscales of role and relationship issues, sexual activity and sexual function were based on 4 (very much), 3 (average), 2 (a little), and 1 (not at all). The frequency of sexual intercourse is based on a special response format: 4 (more than 4 times per month), 3 (3-4 times per month), 2 (1-2 times per month), and 1 (not even

once). If the value for items about sexual function and the frequency of sexual activity is missing, the mean subscale score was inserted in its place. The subscale for 7 additional items were based on 4 (big change), 3 (some change), 2 (little change), and 1 (no change). Higher scores indicate more negative changes of women's sexuality after cancer.

Reliability and validity of the sexuality scale

The face validity of this scale was verified by 2 nursing academics and 1 experienced oncology nurse. A pilot study was conducted among 30 Chinese cervical cancer survivors prior to the beginning of this research. After completing the sexuality scale, respondents were debriefed individually or in groups to identify problems or ambiguities in the items.

The scale's reliability was established among 156 Chinese gynecologic cancer survivors in this study. The reliability of the internal consistency for the whole scale was 0.853 by Cronbach's α. The internal consistency of all subscales' (except that of body image) was higher than 0.70 (role and relationship subscale-0.717, sexual activity subscale-0.773, sexual function subscale 0.772, and the subscale of additional items-0.901). Exploratory factor analysis was performed to establish the construct validity of this scale. Factor loadings greater than ± 0.40 indicate variables important to that factor. The factor loadings (absolute value) of 5 items within the body image subscale were below 0.40. All other items had loadings (absolute value) ranging from 0.405-0.872. Total explained variance by these 27 items was 70.879%, and principle component analysis indicated a five-factor solution (the subscale of role and relationship were resolved into 2-factor), matching the theoretical hypothesis. Factor analysis results were listed in Table 3-1.

Table 3-1 Factor analysis results of the sexuality scale for gynecologic cancer survivors

	Factor Loading				
Items	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
RR1					.418
RR2					.488
RR3					.415
RR4					.490
RR5			.676		
SA1				.523	
SA2				.478	
SA3				.496	
SA4				.414	
SA5				.443	
SF1	.405				
SF2	.496				
SF3	.427				
SF4	.443				
SF5	.453				
SF6	.497				
SF7	.461				
SF8	.458				
SF9	.623				
SF10	.557				
AD1		.872			
AD2		.630			
AD3		.567			
AD4		.716			
AD5		.708			
AD6		.650			
AD7		.756			

Total explained variance 70.879%

Abbreviation: RR-Role and Relationship issues, SA-Sexual Activity, SF-Sexual Function, AD-Additional items.

In the third study stage, all nurses were asked to fill in a demographic sheet and the 50-item inventory (Appendix 5, 6). The demographic sheet for this stage was used to collect nurses' socio-demographic information, such as age, education level, marital status, work experience, work position, and hospital type in which they were working.

The questionnaire for nurses

The 50-item inventory consisted of four parts. In Part 1, an established Sexuality Attitude and Beliefs Survey (SABS) was adopted for use, containing 12 items that measure attitudes and beliefs concerning addressing sexuality in nursing practice (Magnan et al., 2005). The reliability and validity of this original version of the SABS were established in numerous previous studies: the internal consistency by Cronbach's α ranged from 0.74-0.82 and with good test-retest reliability ($r = .85$; $p < .001$) over a 7- to 10-day interval (Reynolds & Magnan, 2005; Magnan & Reynolds, 2006; Magnan & Norris, 2008). The SABS was translated into Chinese by three academics who are fluent in both English and Chinese, and was tested among 199 Chinese oncology nurses: the internal consistency by Cronbach's α was 0.698, and the known-group validity of the translated Chinese SABS is able to differentiate among nurses working among different units in a hospital (Zeng et al., 2010b). As this forward translation of SABS has an acceptable level of reliability and validity, the SABS used in this study did not perform backward translation.

Parts 2, 3, & 4 were newly-developed items based on relevant literature and tools (Algier & Kav, 2008; Hautamaki et al., 2007; Kong et al.; 2009; Lenahan, 2004; Quinn, 2003; Stead et al., 2003; Tsai, 2004). Part 2 consisted of 10 items that sought information about the extent of practice in addressing patients' sexuality concerns. Part 3 consisted of 8 items relating to possible facilitators for addressing sexuality concerns in nursing practice. Part 4 included 20 items covering possible barriers to addressing sexuality concerns, with barriers related to nurses, patients, limitations related to work organization, and prejudices or myths about cancer.

Response formats of the questionnaires for nurses

In Parts 1-4, participants were asked to respond to items constructed in a Likert-scale format from strongly agree to strongly disagree (scores ranging from 1 to 6). The higher the scores in Part 1, the more it indicates a negative attitude on the part of

nurses towards addressing sexuality with their patients. Higher scores in Part 2 indicate that patients' sexuality concerns were being addressed more frequently in practice. In Part 3, all items were worded positively, so higher scores indicate higher levels of facilitators. All items in Part 4 were worded negatively, so higher scores indicate higher levels of barriers to addressing the sexuality concerns of gynecologic cancer patients.

Reliability and validity of the questionnaire for nurses

The face validity of Parts 2 - 4 was verified by 3 Chinese nurse academics. A pilot study was conducted among 55 nurses working in cancer units. The internal consistency was established by Cronbach's α at 0.873, 0.786 and 0.855 in Parts 2, 3 and 4 respectively. In this study, the internal consistency and reliability were established by Cronbach's α at 0.874, 0.803, and 0.888 in Parts 2, 3, and 4 respectively (n = 202). Exploratory factor analysis shows that all items had loadings ranging from 0.660 to 0.851 (Part 2), 0.596 to 0.903 (Part 3), and 0.513 to 0.845 (Part 4). Total explained variance was 60.73% (Part 2), 57.15% (Part3), and principle component analysis indicated a five-factor solution and explained 60.73% of variance (Part 4).

3.2.4 Data analysis

Data analysis for the qualitative data

Thematic content analysis, as proposed by Burnard (1991), was adapted to analyze these qualitative data. The detailed process and strategies of the data analysis were as follows. The written narratives were read through as transcripts by the researcher, who tried to immerse in the data to obtain a general understanding of themes within the transcripts. The researcher then read all the transcripts again carefully, writing down as many headings as possible to describe all aspects of QOL among Chinese cervical cancer survivors. All the headings were written in a list, with similar headings grouped together and developed into a temporary list of categories and sub-categories.

The temporary list was then compared with the raw written narratives, and the final list of categories and sub-categories were produced, covering all aspects of the narratives contents.

The researcher made extra copies of all transcripts, and used colored pens to highlight the statements that reflect the categories and sub-categories and differentiate them by color. The researcher then cut out each statement and pasted it onto a sheet under the appropriate category and sub-category heading. All of the sheets were filed together according to their headings, to prepare for writing up the findings. Two researchers (the researcher student and the academic supervisor) worked separately to categorize the statements before meeting to discuss and agree on the categories.

Rigor in qualitative study

Rigor in qualitative study is assured through the trustworthiness of findings, when credibility, confirmability and transferability are achieved (Speziale & Carpenter, 2007). The term of credibility is related to internal validity, which refers to the 'truth' of findings (Lincoln & Guba, 1985). This study recruited participants with the appropriate experience related to cervical cancer and its impacts on quality of life. It is one of ways to enhance the truth value of findings through suitable sampling strategy (Creswell, 2007). In addition, by adopting the 'member checks' strategy, it also ensured that the findings were true to the informants' expressed meanings (Morse & Field, 1996), and confirmed that the informants recognized that the interpretation of their expressed experience.

Confirmability is a process criterion to illustrate as clearly as possible the evidence and thought processes that led to the conclusion (Speziale & Carpenter, 2007). This is similar to reliability in quantitative research (Lincoln & Guba, 1985). This process criterion was achieved by an audit trail: the academic supervisor of this study used the

thematic content analysis to perform on the same set of data independently, yielding similar findings.

Transferability refers to the probability that the study findings have meanings to others in similar situations (Speziale & Carpenter, 2007). This criterion is similar to the generalizability in quantitative research. Although the goal of qualitative research is not to produce generalization, the transferability criterion focused on general similarities of findings under similar contexts or circumstances (Leininger, 1994). Threats to the transferability of the findings were minimized due to the diverse representation of the participants' age range and the survival length.

Data analysis for the quantitative data

All the quantitative data were entered and analyzed using SPSS Statistics 17.0 (SPSS Inc. Chicago, Illinois). In the second stage, descriptive statistics were used to describe respondents' demographic and medical information, and the sexuality issues of Chinese gynecologic cancer survivors. Inferential statistics included the use of Cronbach's α, factor analysis, binary logistic regressions. In the third stage, descriptive statistics were used to describe respondents' demographic characteristics, mean SABS scores and nursing practice scores. Inferential statistics included the use of factor analysis, Spearman's rank coefficients and Hierarchical regression analysis.

3.2.5 Ethical consideration

Ethical approval was obtained from the Hong Kong Polytechnic University and all hospitals before the commencement of this study. Information sheets (Appendix 7, 8, 9, 10) about the purpose of this study were provided for all participants to explain the aim of this study. Consent forms (Appendix 11, 12, 13, 14) were given to all potential participants to ensure the participation in a voluntary base. After participants' consent obtained, the researcher further explained the process of data collection and reassured that they could withdraw from the study at any time. A code number was used to

ensure anonymity. To maintain the confidentiality of the research data, the raw data could only be accessed by the researcher.

3.3 Summary

This chapter presents study objectives and study methods. Study stage 1 adopted the qualitative approach to explore the meanings of QOL among Chinese cervical cancer survivors and the impact of cervical cancer survivorship on these women's QOL. Open-ended questions by written narratives were adopted to obtain information on Chinese cervical cancer survivors' perceptions of QOL. Stages 2 & 3 were using the quantitative approach to describe the sexuality concerns of Chinese gynecologic cancer survivors, and to explore Chinese nurses' attitudes and practice related to sexuality care in nursing practice respectively.

Part 3
Study Results

Chapter 4: Quality of Life Issues from Chinese Patient Perspectives

Chapter 5: Sexuality Issues from Chinese Patient Perspectives

Chapter 6: Addressing Sexuality Issues from Chinese Nurse Perspectives

Chapter 4
Quality of Life Issues from Chinese Patient Perspectives

4.1 Demographic and medical characteristics of cervical cancer survivors

This study took place in a tumor hospital. A total of 42 eligible women were accessed and invited. Thirty-five women responded to the invitation to provide a narrative account of their experience.

Demographic and medical characteristics data of these 35 informants show in Table 4-1. A majority of the survivors of cervical cancer were in their 30s (14 out of 35 women) or 40s (13 out of 35 women). Eighteen had high school education or above. Ten were working at the time of data collection. Twenty-three out of 35 women had been unemployed since their cancer diagnosis. Most were married but 9 divorced after their cancer diagnosis. Twenty survivors of cervical cancer were diagnosed in the early stages, but there were three women with an advanced stage of diagnosis. Fourteen informants had undergone surgery. Eighteen had received a combination of cancer treatments (Surgery, Chemotherapy, or Radiotherapy). Fifteen respondents had 1-2 years of post-primary treatment.

Table 4-1 Demographic and medical characteristics of informants

Characteristics	**N = 35** **n (%)**
Age	
< 20 years	1 (2.9)
20-29 years	2 (5.7)
30-39 years	14 (40.0)
40-49 years	13 (37.1)
≥50 years	5 (14.3)
Education levels	
Primary school or below	17 (48.6)
High school or diploma	8 (22.9)
College Diploma	9 (25.7)
University degree	1 (2.9)
Employment status	
Employed	10 (28.5)
Unemployed (before diagnosis)	1 (2.9)
Unemployed (after diagnosis)	23 (65.7)
Retired	1 (2.9)
Marital status	
Single	1 (2.9)
Married	24 (68.6)
Divorce (after diagnosis)	9 (25.7)
Widowhood	1 (2.9)
Stages of disease diagnosis	
Early stage	20 (57.1)
Middle stage	12 (34.3)
Middle to Advanced stage	3 (8.6)
Types of treatment	
Surgery	14 (40.0)
RT or CT	3 (8.6)
Surgery and RT	5 (14.3)
Surgery and CT	7 (20.0)
Surgery and CT and RT	6 (17.1)
Time since post primary treatment	
<0.5 year	5 (14.3)
0.5-1 year (<1 year)	6 (17.1)
1-2 years	15 (42.9)
3-5 years	7 (20.0)
6-10 years	2 (5.7)

Abbreviation: RT - Radiation therapy, CT - Chemotherapy

4.2 Meaning of quality of life

In response to the question, "could you please describe the meaning of 'quality of life' in your own words?" the major components/indicators about the meaning of QOL as perceived by Chinese cervical cancer survivors are listed in Table 4-2.

Table 4-2 The meaning of quality of life perceived by Chinese women

Health condition:
Good health/health condition and free of disease (CCS 3, 9, 15, 16, 17, 19, 20, 24, 26, 29, 30-35)
Issues related to daily living:
Normal living (CCS16 & 21)
Having basic living materials (CCS11)
Regular living habits such as eating, sleeping and entertaining activities (CCS18)
Living independently, having a good standard of living (CCS2, 4, 10, 23, 25 & 28)
Being happy (CCS9, 16, 29, 24 & 29)
Having hope for the future (CCS 20 & 22)
Being easily satisfied with life (CCS15)
Social relationships:
The quality of relationship with society, good social relationship, the quality of interpersonal relationship with friends and colleagues (CCS4, 13, 20 & 24)
Financial condition:
QOL depending on financial condition and having to save as much as possible to afford the cost of cancer treatments and living expenses (CCS1)
Financial condition, good financial conditions, enough money to use (CCS12, 13, 15 & 27)
Family issues:
Family harmony or having a harmonious family atmosphere, people and things in the family running smoothly, good family relationship (CCS7, 9, 13, 17, 18, 25, 28 & 34)
Work-related issues:
Working conditions, being able to independently finish work, good quality of work and recognition from colleagues (CCS 4, 14, 15 & 31)
Issues related to sex life:
The importance of sexual activity and the harmony of sex life and sexual relationship with husband/ partners (CCS7, 12, 17, 26 & 29)

Abbreviation: CCS - cervical cancer survivor

The most common one was 'QOL' meant being in a good health condition and free of disease. The second component was women's concerns on daily living, such as normal living, being happy, having hope for the future, and having a good living standard. As survivors of cervical cancer, some of the informants perceived living

independently as one of the components of QOL. Other issues related to daily living included regular living habits and being easily satisfied with life.

The third component was about social and interpersonal relationships such as the quality of relationship with family members, colleagues and society at large. The fourth component concerned financial conditions such as having enough money to afford the cost of cancer treatment. The fifth component was related to family issues: having a happy family, or having good and harmonious family relationships. The sixth component was about work-related issues: working conditions, being able to work independently, and having the quality of one's work recognized by colleagues. The final one was related to sex life. Some women took sexual activity and the harmonious sexual relationship with their husbands/partners as important indicators of their QOL.

4.3 The impact of cervical cancer survivorship on Chinese women's QOL

The analysis of written narratives related to the impact of cancer survivorship on their QOL, there were seven themes and a variety of subthemes emerged.

4.3.1 Physical health worry

Physical health worries included loss of appetite, poor sleep quality, loss of hair and weight changes due to cancer treatment, premature menopause symptoms due to ovarian removal surgery or ovarian failure, constipation and dysuria:

> I was very sensitive to radiotherapy; after treatment I had no appetite and poor quality of sleep. Also, my immune system was weaker than before, so that I caught cold easily…(CCS3).
>
> …leg edema and hyperspasmia, hot flushes, midnight sweating, and severe constipation…(CCS12, 18).

4.3.2 Psychological health concerns

The diagnosis of cervical cancer or treatment may also have negative psychological sequelae: anxiety, depression, becoming irritable, feeling guilty due to burdening the family, feeling fatigue and worrying about disease. Fear of cancer recurrence was one common negative psychological concern. Other subthemes were including with sense of vulnerability, such as feeling unable to control one's health, reduced self-esteem and sense of self (the way of viewing oneself):

> One year after surgery, my mood was not stable and I would have significant mood swings; I felt more irritable, worried about the disease and afraid of cancer recurrence…(CCS18).
>
> Sometimes I felt very anxious and worried about the possible recurrence of cancer, resulting in sleeplessness, feeling dirty and had no sense of self (CCS9, 31).

4.3.3 Feeling of social isolation

Although some women reported no changes in their daily lives, more than half described cancer as having negative impacts on their social functioning, including narrowed social networks, and feeling isolated:

> After the cancer diagnosis, I quit my job. Just staying in home and having nothing to do, I felt isolated (CCS20).
>
> …I lost my job due to my disease (cancer); my social networks were narrowed as a consequence…(CCS29)

4.3.4 Being a burden to family

Relevant impacts included concerns regarding family members' living conditions and placing an emotional burden on their husband:

> …worrying about my disease influenced my family members' quality of life, especially for my children. Since getting the disease (cancer), I had become

> more irritable. Sometimes I would quarrel with my husband. Now the whole family suffered from lots of pressure (CCS15, 28).

The other aspect was the financial burden placed on the family, such as having to afford cancer treatment costs:

> In order to come to hospital to undertake systematic treatment, all my family members have to save as much possible in daily living. In order to pay for my treatment, my whole family borrowed a lot of money from others. Particularly since I haven't returned to work, I am under a lot of financial pressure (CCS1).

4.3.5 Disruptions to sexual life

There were negative changes in the women's sex lives. Since the diagnosis and treatment of cervical cancer, a majority of survivors (13 out of 35) had not resumed sexual activities. Reasons included having no husband/partner, being too tied to have sex, fear of sexual activities having a negative impact on disease recovery or weakening the potency of cancer treatment, and their husband not initiating sexual activities:

> Since the surgery, there has been no sexual activity, as I am worried that sexual intercourse may influence the effect of treatment…(CCS1).
>
> Before the surgery, our sex life was really good. Since the surgery, there has been no sexual activity. My husband and I sleep in different beds: relevant factors include fear of disease, the negative impact of thinking about sexual intercourse, and the lack of sexual desire (CCS9).

Some women reported that they were currently sexually active but with reduced frequency or/and quality of sexual activities, because of vagina dryness, dyspareunia, worrying about disease, husband/partners having poor health problems, and aging problems resulting in lack of energy:

> Sexual activities were very few, due to aging problem and my husband' poor health condition (CCS5, 22).
>
> The frequency was the same but…the quality of our sex life is not as good. There are lots of factors, including vaginal dryness, pain during sexual intercourse, and my husband also being afraid of contracting the disease…(CCS7).

4.3.6 Sources of social support

Participants had numerous sources of support for coping with their disease. The most common one was caring and psychological/social supports from the family. Some women even reported that their family members gave them too much support:

> …my family members always tell me that my life is not just belonging to myself. No matter what happens, I have to live for my family (CCS3).
>
> All family members very emphasized my health conditions. They did whatever they could for me. But I don't want to get so much caring, it (family members' caring and support) has adverse effects on me and let me feel depressed (CCS4).

Also, women may obtain support and care from their relatives, friends and colleagues:

> My neighbor and colleagues' support and caring let me come through all those hard time during my treatment (CCS18, 25).

Other women were just facing and accepting the reality as one coping strategy. By using of positive life beliefs or religion beliefs, one woman reported 'Buddhism' as one way for coping with disease:

> Just acceptance the reality and trying to lead to normal life, difficulties always exist but I believe that there are many ways to conquer difficulties (CCS16, 30).

> Coping with disease included relative's support, relying on Buddhism…(CCS9).

Other strategies were by forgetting about the disease, paying little attention on the status of patients, and just struggling for living:

> …don't always think about I am a patient... forgetting about disease and less emphasis on the status of patients (CCS21, 24).

Finally, one informant reported relying on professional counseling to cope with the disease:

> At the beginning of treatment, I had lost heart in life. Fortunately, my friends brought me a psychological counseling clinic. By professional counseling, I benefited a lot and gradually have courage to carry on my life (CCS4).

4.3.7 Changes of life outlook and better family relationships

Women also reported certain positive gains from their cancer experience. These changes included more positive life outlooks, such as a more positive attitude toward life, treasuring life, appreciating relationship with others, viewing the cancer experience as a rebirth, the relationship with their husband becoming more intimate, and their family relationship become more harmonious.

> …compared with before I had cancer, now I have a more positive outlook on life and enjoy it every day (CCS1).
>
> Compared with before the cancer, my relationship with my husband has become more intimate, I am more content with life and more aware of my health, and I treasure life and feel grateful to be alive (CCS17, 20).

4.4 Summary

This chapter reported study findings at study stage 1. The meanings of QOL perceived by 35 Chinese survivors of cervical cancer included being free of disease, having a

good standard of living, having a harmonious family atmosphere, being able to work independently, and having a harmonious sexual life. The impact of cervical cancer on Chinese women's QOL includes physical and psychological sequelae, family distress, financial burden and disruptions to social function and sex life. Nevertheless, positive gains reported among these survivors included changes of life outlook, treasuring life and better family relationships. Study findings revealed that Chinese cervical cancer survivors identified their sexual life/activities as one of important aspects of QOL. It is necessary to raise nurses' and other healthcare providers' awareness on addressing women's sexuality-related concerns in practice.

Chapter 5
Sexuality Issues from Chinese Patient Perspectives

5.1 Participants' demographic and medical characteristics

Among these 3 studied hospitals, a total of 180 subjects were accessed in this study. Twenty-four outpatients refused to participate, either because they did not have time or due to the sensitive nature of this research topic. As a result, only 156 Chinese gynecologic cancer survivors were included in this report, yielding a response rate of 86.7%.

Demographic and medical characteristic data in Table 5-1 show that 34% of participants were in their 50s or older. A majority of participants (66.6%) had primary school or a lower education level. Nearly half (48.7%) were unemployed. Almost all participants (93.6%) were married, and many of them (89.7%) had children. More than half of women (53.2%) had an advanced stage of cancer. Thirty-two per cent were having a single type of treatment, while the remainder were receiving a combination of cancer treatments. More than half of participants (60.3%) had just completed their initial cancer treatment (within half a year). Nearly three quarters of the women had a diagnosis of cervical cancer.

Table 5-1 Demographic and medical characteristics of participants

Characteristics	No. (%) (n = 156)
Age group, y	
20-29	7 (4.5)
30-39	39 (25.0)
40-49	57 (36.5)
≥50	53 (34.0)
Education level	
Primary school or below	104 (66.6)
High school	19 (12.2)
College or above	33 (21.1)
Employment status	
Employed	57 (36.5)
Unemployed	76 (48.7)
Retired	23 (14.7)
Marital status	
Married	146 (93.6)
Divorced	5 (3.2)
Widowed	5 (3.2)
Motherhood	
No	16 (10.3)
Yes	140 (89.7)
Disease stage	
Early stage	73 (46.8)
Advanced stage	83 (53.2)
Types of treatment	
Surgery	37 (23.7)
RT	13 (8.3)
Surgery + RT	24 (15.4)
Surgery + CT	31 (19.9)
Surgery + RT + CT	48 (30.8)
RT + CT	3 (1.9)
Time since completing initial treatment, y	
<0.5	94 (60.3)
0.5-1	36 (23.1)
2-5	20 (12.8)
>5	6 (3.8)
Types of cancer	
Cervical cancer	115 (73.7)
Others	41 (26.3)

Abbreviation: RT- Radiation therapy, CT- Chemotherapy

Note. Others-including ovarian, uterine and vulva cancer

5.2 Sexuality issues among Chinese gynecologic cancer survivors

5.2.1Body image among participants

The percentage of agreement or disagreement was undertaken by dichotomizing item response options between 2 and 3: the response of 1-2 and 3-4 were taken as disagreement and agreement, respectively. As shown in Table 5-2, more than half of the women (64.1%) like their appearance, and 70.5% of them think that they were physically attractive. In addition, nearly 70% of the women like their looks, and 51.9% of them viewed their body being sexually appearing. Overall, these participants were with positive feelings about their body image.

Table 5-2 Sexuality issues among Chinese gynecologic cancer survivors

In the past month	n (%)	n (%)	n (%)	n (%)
Body image	Agreement	Disagreement		
1. You dislike your appearance	56 (35.9)	100 (64.1)		
2. You like your looks just the way they are	109 (69.9)	47 (30.1)		
3. Most people would consider you good-looking	99 (63.4)	57 (36.6)		
4. You are physically unattractive	46 (29.5)	102 (70.5)		
5. Your body is sexually appealing	81 (51.9)	75 (48.1)		
Role and relationship issues	Very much	Moderate	No impact	
6. Has cancer affected your sense of femininity?	21 (13.5)	101 (64.7)	34 (21.8)	
7. After cancer treatment, has cancer affected the way your partner feels about you as a woman?	24 (15.4)	103 (66.1)	29 (18.6)	
8. Has cancer affected your role as a sexual partner?	14 (9.0)	84 (53.9)	58 (37.2)	
9. Has cancer affected your role as a mother?	9 (5.8)	57 (36.5)	90 (57.7)	
10. Has cancer affected your overall sexual relationship with your intimate partner?	19 (12.2)	89 (57.1)	48 (30.8)	
Sexual function	Very much	Average	A little	Not at all
11. Are you worried about your partner's overall sexual function?	16 (10.3)	34 (21.8)	38 (24.4)	68 (43.6)
12. Are you worried about your overall sexual function?	18 (11.5)	24 (15.4)	55 (35.3)	59 (37.8)
13. Did you feel any sexual desire this month?	7 (4.5)	28 (18.0)	47 (30.1)	74 (47.4)
14. Did you feel dryness in your vagina during intercourse?	11 (7.1)	27 (17.3)	52 (33.3)	66 (42.3)
15. Have you had any pain or discomfort during sexual intercourse?	8 (5.1)	29 (18.6)	45 (28.8)	74 (47.4)
16. Have you experienced bleeding during intercourse?	11 (7.1)	15 (9.6)	52 (33.3)	78 (50.0)
17. Did you feel that intercourse was bothersome because your vagina felt too small?	6 (3.8)	14 (9.0)	53 (34.0)	83 (53.2)
18. Were you able to complete sexual intercourse?	4 (2.6)	19 (12.2)	57 (36.5)	76 (48.7)
19. Have you reached orgasm?	11 (7.1)	30 (19.2)	45 (28.8)	70 (44.9)
20. Did you feel satisfied after having sex?	8 (5.1)	41 (26.3)	40 (25.6)	67 (42.9)
Sexual activity				
21. Was 'having sex' an important part of your life?	23 (14.7)	77 (49.9)	23 (14.7)	33 (21.2)
22. Have you had sexual activity this month?	13 (8.3)	59 (37.8)	38 (24.4)	46 (29.5)
23. Did you enjoy sexual activity this month?	7 (4.5)	24 (15.4)	26 (16.7)	99 (63.5)
24. How frequently did you have sexual intercourse this month?	1 (0.6)	21 (13.5)	24 (15.4)	110 (70.5)
	>4 times	3-4times	1-2times	Not at all
25. Are you satisfied with the frequency of sexual intercourse this month?	3 (1.9)	43 (27.6)	20 (12.8)	90 (57.7)

5.2.2 Role identity and sexual relationships among participants

Table 5-2 also shows data regarding role and sexual relationship issues of these gynecologic cancer survivors. The impact of cancer and its treatment on women's role identity and function was classified into 3 levels: severe impact, moderate impact (response options 2 and 3 were taken as a moderate level of impact), and no impact. A majority of women (64.7%) reported that cancer has moderate impact on their sense of femininity. Similarly, it affected women's role as sexual partners (62.9%). Although 30.8% of participants reported that cancer has no impact on their overall quality of sexual relationship, 19 women (12.2%) indicated that cancer has severe impact on their sexual relationship with partners.

5.2.3 Sexual function issues among participants

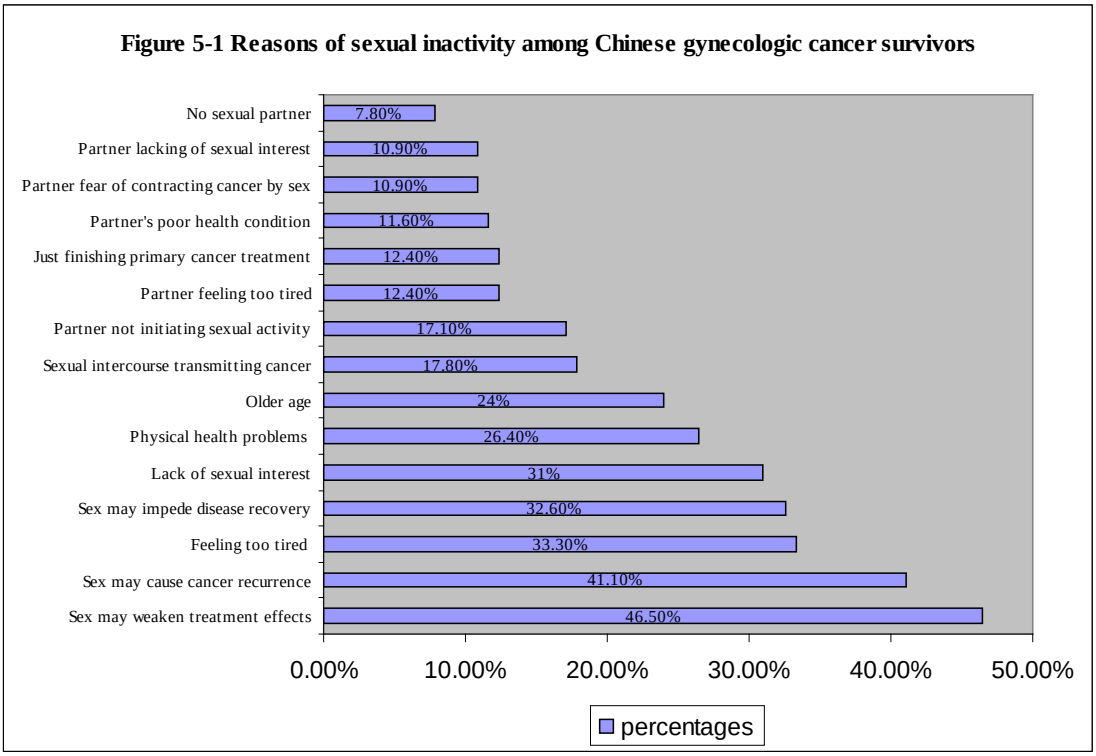
More than half of women were worried about their own overall sexual function (62.2%), with 11.5% being 'very worried'. Most (77.5%) reported little or no sexual desire. More than half (57.7%) of them reported the problem of vaginal dryness, and 52.6% of women had experienced pain or discomfort during sexual intercourse. Fifty per cent of participants reported the experience of bleeding during intercourse. Most of the women (85.2%) reported feeling unable to complete sexual intercourse, difficulty in reaching orgasm (73.7%), and feeling unsatisfied with sex (68.5%). The detailed information about women's sexual function was summarized in Table 5-2.

5.2.4 Issues of sexual activity and reasons of sexual inactivity among participants

Table 5-2 also shows these Chinese women's reports of their sexual activity. Most of the Chinese women (78.8%) viewed sexual activity as at least 'a little' important part of their life. While only a few of them (29.5%) had not engaged in intimate sexual activities in the past month, most participants (70.5%) did not engage in sexual intercourse. More than half of these women neither enjoyed their sexual activity nor were satisfied with the frequency of their sexual intercourse.

The reasons of sexual inactivity during the past month are shown in Figure 5-1. Most common reasons include “sex may weaken the effect of cancer treatment” (46.5%), “sex may cause cancer recurrence” (41.1%), “feeling too tied” (33.3%), “worrying about sex may impede disease recovery” (32.6%), and “lack of sexual interest” (31%). Issues related to women’s partners were also identified as “partner not initiating sexual activity” (17.1%), “partner’ poor health conditions making difficult to having sex” (11.6%), “partner lacking of sexual interest “ (10.9%), and “partner fear of infecting cancer by sex” (10.9%).

Figure 5-1 Reasons of sexual inactivity among Chinese gynecologic cancer survivors



5.3 Pre-post cancer comparison of sexuality issues among Chinese women

When looking sexuality issues after cancer treatment, there were significant negative changes in their sexual activity, function and sexual relationships. Many of the women (76.9%) reported a reduction in the frequency of sexual activity. Three quarters of them reported a decrease of sexual interest/desire, and 57.5% of participants reported that their overall sexual relationship with partners was negatively

impacted after the diagnosis and treatment of gynecologic cancer. Detailed information is shown in Table 5-3.

Table 5-3 Pre-post cancer comparison of sexuality issues among Chinese gynecologic cancer survivors

Compared with sexuality issues after cancer treatment	Negative changes n (%)	No changes n (%)
26. Has your interest in sexual activity changed?	117 (75.0)	39 (25.0)
27. Has the frequency of your sexual activity changed?	120 (76.9)	36 (23.1)
28. Has your preference regarding types of sexual activity changed?	102 (65.4)	54 (34.6)
29. Has the dryness of your vagina changed?	102 (65.4)	54 (34.6)
30. Do you feel that the size of your vagina has changed?	95 (60.9)	61 (39.1)
31. Has the pain you experience during sexual intercourse changed?	102 (65.4)	54 (34.6)
32. Has the quality of your sexual relationship with your partner changed?	90 (57.7)	66 (42.3)

Predictors of negative changes in sexuality issues among Chinese women by logistic regression were shown in Table 5-4. Women over 50 reported significantly worse outcomes in terms of loss of sexual desire/interest (OR 3.64, 95% CI 1.19-11.16), and reduced frequency of sexual activity (OR 3.19, 95% CI 1.40-7.31) compared to their younger counterparts. Women from lower educational backgrounds reported a more negative impact of the overall quality of sexual relationship (OR 0.43, 95% CI 0.21-0.92) compared to their more educated peers. For treatment type, women who received radiation therapy reported more negative changes in terms of vagina dryness (OR 2.27, 95% CI 1.09-4.72), and pain experienced during intercourse (OR 2.38, 95% CI 1.20-4.69) when compared to women receiving other forms of treatment. Types of cancer were significantly associated with the overall sexuality of gynecologic cancer survivors, this finding should be interpreted with caution due to small number of ovarian, uterine and vulva cancer survivors included in this study. Even though larger numbers of women reported changes in perceived vaginal size and preferred sexual activities as reported above, the demographic and medical variables examined in this logistic regression analysis were not found to be predictive of outcome of change experienced post cancer treatment.

Table 5-4 Predictors of negative changes in sexuality issues among Chinese gynecologic cancer survivors by logistic regression

Variables & Predictors	**B**	**SE**	**OR**	95% **CI** for **OR**		***P*** value
				Low	Up	
Has your interest in sexual activity changed?						
Age (<50y vs. ≥50y)	1.291	0.572	3.637	1.186	11.156	**0.024**
Has the frequency of your sexual activity changed?						
Age (<50y vs. ≥50y)	1.161	0.422	3.193	1.396	7.305	**0.006**
Time since completing initial treatment (<0.5y vs. ≥0.5y)	-0.885	0.444	0.413	0.173	0.987	**0.047**
Has your preference regarding types of sexual activity changed?						
-	-	-	-	-	-	NS
Has the dryness of your vagina changed?						
Types of treatment (no RT vs. with RT)	0.819	0.373	2.269	1.092	4.716	**0.028**
Do you feel that the size of your vagina changed?						
-	-	-	-	-	-	NS
Has the pain you experience during sexual intercourse changed?						
Types of treatment (no RT vs. with RT)	0.865	0.347	2.376	1.204	4.689	**0.013**
Has the quality of your sexual relationship with your partner changed?						
Education level (low vs. high)	-0.835	0.382	0.434	0.205	0.917	**0.029**
Types of cancer (Cervical cancer vs. others)	1.543	0.399	4.679	2.142	10.222	**<0.001**

Note. B- Regression coefficient for each variable in the logistic regression; Others-including ovarian, uterine and vulva cancer
Abbreviation: SE-Standard error; OR-Odds ratio; CI-Confidence interval; NS-No significance; RT-Radiation therapy

5.4 Summary

This chapter reported the study results of stage 2. A total of 156 Chinese gynecologic cancer survivors were included in this stage. Study results revealed that the participants (63.9%) were generally positive towards their own body appearance. However, a large percentage (69.3%) of the women reported that cancer had influenced their overall quality of life in terms of sexuality and intimate relationships. Sexual dysfunction was an important concern among these women (62.2%). The rate of sexual inactivity (70.5%) was relatively high. Reasons for sexual inactivity were related to worry about possibly weakening the potency of treatment (46.5%), fear of cancer recurrence (41.1%), and lack of sexual interest (31%). When looking at predictors of sexuality after cancer treatment, this study found that older age (>50 years old) was associated with the decrease of sexual desire/interest (OR 3.64, CI 1.19-11.16). Women who received radiation therapy suffered from more severe vaginal dryness (OR 2.27, CI 1.10-4.72) and were less sexually active than those who did not have radiation therapy.

Chapter 6
Addressing Sexuality Issues from Chinese Nurse Perspectives

6.1 Demographics of participants

Among these 6 studied hospitals, the total number of eligible nurses in the gynecologic units was 243. Only 202 questionnaires were completed and included in this report, giving a response rate of 83.1%.

All participants were female nurses working in gynecologic cancer units in the three abovementioned cities in China. Nearly 60% were between 21 and 30 years old. Nearly half (49.5%) had been working in cancer units for 6 to 20 years. Forty-five per cent were Nurse-in-Charge. Most had either a diploma or an associate degree (84.6%). More than half (61.4%) were married. Participants came from two types of hospitals: tumor hospitals (49%, *n* = 99) and general hospitals (51%, *n* = 103). Detailed information on these 202 nurses' demographics is shown in Table 6-1.

Table 6-1 Demographics of Chinese nurses (N=202)

Characteristics	n (%)
Age (years)	
≤20	5 (2.5)
21-30	121 (59.9)
31-40	65 (32.2)
41-50	11 (5.4)
Work experience (years)	
<1	28 (13.9)
1-5	56 (27.7)
6-10	54 (26.7)
11-20	46 (22.8)
>20	18 (8.9)
Work position	
Nurse	14 (7.0)
Experienced Nurse	57 (28.2)
Nurse-in-Charge	91 (45.0)
Nursing Officer	40 (19.8)
Education level	
Diploma	96 (47.5)
Associate degree	75 (37.1)
Bachelor's degree	29 (14.4)
Master's degree	2 (1.0)
Marital status	
Single	77 (38.1)
Married	124 (61.4)
Missing values	1 (0.5)
Hospital type	
Tumor hospital	99 (49.0)
General hospital	103 (51.0)

6.2 Nurses' attitudes and beliefs regarding patients' sexuality concerns

Table 6-2 shows the distribution of nurses in agreement or disagreement with the attitudes and belief statements regarding patients' sexuality concerns. The percentage of disagreement or agreement was undertaken by dichotomizing item response options: those who chose the options of 1-3 (strongly disagreed, disagreed and slightly disagreed) and 4-6 (slightly agreed, agreed, strongly agreed) were classified as being in disagreement or agreement respectively. The mean and standard deviation (SD) are also shown in Table 6-2, with positively stated items reversely scored to calculate the means. The higher the mean scores, the more negative the nurses' attitudes regarding patients' sexuality concerns. In this study, the total SABS score ranged from 27 to 67 (M = 44.94 SD 8.12)

Table 6-2 Nurses' attitudes and beliefs regarding sexuality concerns of gynecologic cancer patients

Items in SABS	M (*SD*)	Agreement (%)	Disagreement (%)
Negatively stated items			
1. Sexuality is too private an issue to discuss with patients (SABS1)	4.70 (1.45)	77.7	22.3
2. Most hospitalized patients are too sick to be interested in sexuality (SABS2)	4.14 (1.49)	63.4	36.6
3. Sexuality should be discussed only if initiated by patients (SABS3)	3.78 (1.41)	59.4	40.6
4. When patients ask me a sex-related question, I advise them to discuss it with their physician (SABS4)	3.52 (1.44)	52.0	48.0
5. I am uncomfortable talking about sexual issues (SABS5)	3.21 (1.47)	41.6	58.4
Positively stated items[1]			
6. I make time to discuss sexual concerns with my patients (SABS6)	4.12 (1.41)	34.2	65.8
7. I am more comfortable talking about sexual issues with my patients than are most of the nurses I work with (SABS7)	3.99 (1.27)	34.7	65.3
8. I feel confident in my ability to address patients' sexual concerns (SABS8)	3.98 (1.45)	35.1	64.9
9. Patients expect nurses to ask about their sexual concerns (SABS9)	3.68 (1.48)	47.0	53.0
10. Discussing sexuality is essential to patients' health outcomes (SABS10)	3.41 (1.69)	49.0	51.0
11. I understand how my patients' diseases and treatments might affect their sexuality (SABS11)	3.20 (1.38)	57.4	42.6
12. Giving a patient permission to talk about sexuality concerns is a nursing responsibility(SABS12)	3.14 (1.48)	62.9	37.1

[1] Positively stated items were reversely scored for the calculation of means.

The mean SABS score of each item varied from 3.14 to 4.70. Over three quarters (77.7%) of the nurses viewed sexuality as 'too private an issue to discuss', and 63.4% assumed that 'most hospitalized patients are too sick to be interested in sexuality'. These two items had high mean scores, with mean = 4.70 (SD 1.45) and mean = 4.14 (SD 1.49) respectively.

More than half of the Chinese nurses (62.9%) agreed that ‘giving a patient permission to talk about sexual concerns is one of nurses’ responsibilities’, and 57.4% understood how ‘patients’ disease and treatment might affect their sexuality’. However, only 35.1% were ‘confident in their abilities to address issues of sexuality’, 34.7% considered themselves ‘comfortable talking about sexual issues with my patients’, and 34.2% ‘made time to discuss sexual concerns with cancer patients’. The mean scores for these three statements were high at 4.12 (SD 1.41), 3.99 (SD 1.27) and 3.98 (SD 1.45) respectively.

6.3 Facilitators and barriers influencing nursing practice related to sexuality issue discussion in nursing practice

Table 6-3 shows nurses’ agreement with the statements regarding facilitators and barriers influencing nursing practice related to sexuality concerns. The percentage of disagreement or agreement was undertaken by dichotomizing item response options: those who chose the options of 1-3 (strongly disagreed, disagreed and slightly disagreed) and 4-6 (slightly agreed, agreed, strongly agreed) were classified as being in disagreement and agreement respectively. Higher mean scores indicate higher agreement with the facilitators and barriers influencing nursing practice related to the sexuality concerns of gynecologic cancer patients.

Table 6-3 Facilitators and barriers influencing sexuality care in nursing practice

	M (*SD*)	Agreement (%)	Disagreement (%)
Facilitators			
1. Having a good nurse-patient relationship (F1)	4.97 (1.21)	87.6	12.4
2. Possessing good communication skills (F2)	4.74 (1.25)	82.7	17.3
3. Availability of private environment (F3)	4.38 (1.55)	72.3	27.7
4. Possession of sound sexuality knowledge (F4)	4.32 (1.42)	71.3	28.7
5. Provision of relevant training (F5)	4.18 (1.68)	66.8	33.2
6. Patients requesting information related to sexual history and disease (F6)	4.15 (1.71)	64.4	35.6
7. Patients initiating or expressing their sexuality concerns (F7)	3.70 (1.48)	56.9	43.1
8. Sexuality care being included in routine nursing practice (F8)	3.65 (1.61)	56.4	43.6
Barriers			
Prejudices about cancer			
9. Women with cancer having more things to be concerned about than having sex	4.51 (1.51)	72.3	27.7
10. Sexuality representing a low health priority	4.31 (1.43)	71.3	28.7
Organization restrictions			
11. Staff shortages resulting in limited time and energy	4.48 (1.47)	74.8	25.2
12. Limited resources	4.33 (1.40)	72.8	27.2
13. Lack of role modelling	4.20 (1.51)	64.9	35.1
14. Lack of private setting	4.17 (1.50)	68.3	31.7
15. Sexuality care not being part of nursing routine	3.79 (1.74)	55.9	44.1
Nurses' factors			
16. Inadequate education preparation	4.40 (1.65)	68.8	31.2
17. Being afraid of offending patients	4.32 (1.57)	69.3	30.7
18. Lack of relevant experience	4.20 (1.54)	67.8	32.2
19. Limited knowledge	3.98 (1.50)	64.9	35.1
20. Feeling embarrassed at addressing patients' sexuality concerns	3.93 (1.70)	60.9	39.1
Patients' factors			
21. Patients' possible embarrassment at discussing their sexuality concerns	4.39 (1.59)	71.3	28.7
22. Patients concealing information	4.19 (1.48)	65.3	34.7
23. Patients feeling that sexuality assessment is not relevant treatment	4.08 (1.47)	66.3	33.7
24. Patients declining to answer nurses' questions	4.08 (1.45)	65.3	34.7
25. Patients' refusal	3.84 (1.57)	57.9	42.1
Myths about cancer			
26. Fear that sex will weaken the potency of the cancer treatment	2.78 (1.57)	34.7	65.3
27. Cancer may recur if patients have sex after treatment	2.44 (1.60)	27.7	72.3
28. Cancer is contagious	2.33 (1.65)	26.2	73.8

The facilitators influencing nursing practice were 'having a good nurse-patient relationship' (mean = 4.97, SD 1.21), good communication skills (mean = 4.74, SD 1.25), and 'having a private environment available' (mean = 4.38, SD 1.55). More than 80% of nurses agreed that having a good relationship with clients and possessing good communication skills are two facilitators of practice related to sexuality concerns. Only slightly more than half of the nurses agreed that 'sexuality care is included in routine nursing practice' (56.4%), and 'patients initiated or expressed sexuality concerns' (56.9%) were facilitators influencing practice related to sexuality care.

The common barriers related to sexuality care included Chinese nurses' perceptions that 'women with gynecological cancer have more things to be concerned about than having sex' (72.3%,), being 'embarrassed when addressing patients' sexuality concerns' (71.3%), and believing that 'sexuality care represents a low priority' (71.3%). Other related barriers were attributed to organizational restrictions such as 'staff shortages' (74.8%), limited resources (72.8%), and nurses' 'inadequate educational training related to sexuality care' (68.8%).

6.4 Addressing sexuality concerns of patients with gynecologic cancer in nursing practice

Table 6-4 shows nurses' self reports of how frequently they addressed patients' sexuality concerns in practice. They were asked to choose from options 1 to 6, indicating 'never' to 'frequently'. The mean and SD are shown, with negatively stated statements reversely scored to calculate the means. Higher mean scores indicate that nurses addressed the sexuality concerns of patients with gynecologic cancer relatively more frequently in practice. The mean scores for all practice statements varied from 2.15 to 3.15 in the possible range of 1-6, indicating that nurses never, rarely or seldom addressed patients' sexuality concerns in daily practice.

Table 6-4 Addressing sexuality concerns of patients with gynecologic cancer in nursing practice

Nursing Practice	M (*SD*)	Never 1 n (%)	Rarely 2 n (%)	Seldom 3 n (%)	Occasionally 4 n (%)	Sometimes 5 n (%)	Frequently 6 n (%)
1. Discussing concerns of body image changes and effects on sexuality with patients	3.15 (1.55)	41 (20.3)	29 (14.4)	47 (23.3)	45 (23.3)	22 (10.9)	18 (8.9)
2. Discussing the risk of early menopause with patients who are of childbearing age	3.14 (1.60)	45 (22.3)	33 (16.3)	35 (17.3)	43 (21.3)	29 (14.4)	17 (8.4)
3. Providing information/education regarding patients' sexuality concerns	3.12 (1.57)	44 (21.8)	33 (16.3)	34 (16.8)	51 (25.2)	24 (11.9)	16 (7.9)
4. Asking patients about problems in sexual functioning	3.10 (1.77)	61 (30.2)	22 (10.9)	32 (15.8)	34 (16.8)	28 (13.9)	25 (12.4)
5. Telling patients about possible effects of cancer on sexual functioning	3.00 (1.59)	56 (27.7)	25 (12.4)	35 (17.3)	45 (22.3)	30 (14.9)	11 (5.4)
6. Asking patients about possible problems in their sexual relationships	2.81 (1.63)	64 (31.7)	33 (16.3)	33 (16.3)	36 (17.8)	21 (10.4)	15 (7.4)
7. Telling patients about the possible side-effects of cancer treatment on sexuality	2.77 (1.53)	54 (26.7)	42 (20.8)	45 (22.3)	32 (15.8)	14 (6.9)	15 (7.4)
8. Answering patients' questions about sexuality	2.44 (1.44)	77 (38.1)	35 (17.3)	39 (19.3)	32 (15.8)	13 (6.4)	6 (3.0)
9. Listening to patients' concerns about sexuality	2.35 (1.38)	77 (38.1)	41 (20.3)	41 (20.3)	28 (13.9)	8 (4.0)	7 (3.5)
10. Referral to specialist sexuality counseling service	2.15 (1.29)	85 (42.1)	51 (25.2)	29 (14.4)	28 (13.9)	4 (2.0)	5 (2.5)

Nearly 40% of nurses reported that they occasionally, sometimes or frequently discussed with patients 'their concerns of body image changes and effects on sexuality' (mean = 3.15, SD 1.55), and 'the risk of early menopause' in women of childbearing age (mean = 3.14, SD 1.60). By contrast, nearly 80% of nurses never, rarely or occasionally 'listen to patients' sexuality concerns' (mean = 2.35, SD 1.38) and make 'referrals to sexuality counseling services' (mean = 2.15, SD 1.29).

6.5 Predictive factors relating to sexuality care in nursing practice

Hierarchical multiple regression analyses were performed to identify significant predictors for sexuality care in nursing practice. The residuals' normality, linearity, and homoscedasticity had to be checked before multiple regression analysis could be conducted (Tabachnick & Fidell, 2007). All categorical variables were transformed into dummy variables. Relevant screening procedures were also performed. The residuals among these regression models had no outliers and no evidence of singularity.

Three steps of regression were conducted. In the first step, before entering the demographic variables, Spearman's rank correlation coefficients were performed to identify significant demographic variables related to sexuality care in practice. Table 6-5 listed all results. Except for age (r_s = 0.122, p = 0.084), all other variables were significantly correlated to sexuality care in practice. Consequently, work experience, work position, education level, marital status and hospital were entered to predict sexuality care in practice. In the second step, the SABS items and the Facilitator items were entered. In the third step, the sub-domains of Barriers were entered.

The results of these regression analyses are listed in Table 6-6. Work position, marital status and hospital type were statistically significant predictors of sexuality care in nursing practice. These two variables accounted for 23.1% of the variance. Three SABS items (sexuality is too private an issue to discuss with patients-SABS1; most hospitalized patients are too sick to be interested in sexuality-SABS2; when patients ask me a sex-related question, I advise them to discuss it with their physician-SABS4) and three Facilitator items (availability of private environment-F3; provision of sexuality care training-F5; sexuality care being added into routine nursing care-F8) were also found to be statistically significant predictors. These variables account for

27.8% of the variance. Two sub-domains of Barriers explained a further 3.3% of variance. They were prejudices about cancer (women with cancer being concerned about other things than having sex; sexuality representing a low health priority), and nurses' factors (insufficient education preparation, being afraid of offending patients, lack of relevant experience, limited knowledge and embarrassment).

Table 6-5 Correlations of nurses' demographics with the total nursing practice scores

Spearman's rank coefficient (r_s) *P* Value	**Age**	**Years of nursing experience**	**Work position**	**Education levels**	**Marital status**	**Hospital type**
Total nursing practice scores	0.122 0.084	0.239** 0.001	0.283** <0.001	0.377** <0.001	0.219** 0.002	0.391** <0.001

**. $P < 0.01$ (2-tailed).

Table 6-6 Hierarchical regression results with total scores of sexuality care practice as dependent variable

Variables	Model 1		Model2		Model3	
	Std *β*	*P*	**Std *β***	*P*	**Std *β***	*P*
1. Work experience (0=10 years or less, 1=more than 10 years)	.045	.522	.037	.552	.059	.341
2. Work position (0=Experienced Nurse or below, 1=Nurse-in-Charge or above)	.081	.243	.099	.106	.119	.053
3. Education level (0=Diploma, 1= Associate degree or above)	.148	.024	.124	.055	.128	.064
4. Marital status (0=single, 1=married)	.205	.006	.166	.009	.193	.006
5. Hospital type (0=oncology, 1=general)	.246	<.001	.311	<.001	.282	<.001
6. SABS1			-.243	.001	-.201	.001
7. SABS2			-.206	.005	-.241	.008
8. SABS3			-.044	.442	-.043	.465
9. SABS4			-.236	<.001	-.168	.005
10. SABS5			-.075	.250	-.039	.497
11. SABS6			.086	.154	.026	.654
12. SABS7			.105	.139	.128	.064
13. SABS8			.049	.395	.042	.479
14. SABS9			-.111	.147	-.109	.154
15. SABS10			.098	.177	.101	.109
16. SABS11			.083	.229	.050	.397
17. SABS12			.087	.159	.004	.941
18. F1			.064	.407	.117	.097
19. F2			.065	.338	.023	.759
20. F3			.288	<.001	.294	<.001
21. F4			.068	.243	.088	.237
22. F5			.161	.008	.168	.014
23. F6			.137	.055	.123	.065
24. F7			.009	.905	.013	.855
25. F8			.161	.021	.148	.046
26. Barriers - Prejudices about cancer					-.167	.043
27. Barriers - Organizational restrictions					-.047	.496
28. Barriers - Nurse factors					-.195	.014
29. Barriers - Patient factors					-.128	.094
30. Barriers - Myths about cancer					-.109	.112

For regression model 1: F (5, 202) =14.87 (P < .001), Adjusted R^2 = 0.231;
For regression model 2: F (25, 202) =9.26 (P < .001), Adjusted R^2 = 0.509;
For regression model 3: F (30, 202) =7.99 (P < .001), Adjusted R^2 = 0.542.
Abbreviation. Std *β*- Standardized *β* coefficient

6.7 Summary

This chapter presents study results of stage 3. A sample of 202 nurses working in gynecological units in China was recruited. Study results revealed that the majority (77.7%) held the attitude that 'sexuality is too private an issue to discuss with patients'. Only 34.2% 'make time to discuss sexual concerns with patients'. Regression analysis revealed that nurse' marital status and hospital type in which they were working influenced their practice in sexuality care. Nurses' conservative attitudes toward sexuality, their prejudices regarding gynecological cancer, the lack of availability of private environment, the lack of sexuality care training, and the failure to include sexuality care in routine nursing care, were found to be factors that significantly influence sexual care in nursing practice.

Part 4
Discussion and Implications

Chapter 7: Discussion and Limitations

Chapter 8: Implications and Conclusion

Chapter 7
Discussion and Study Limitations

7.1 Discussion of study findings

7.1.1 Culture and the meaning of quality of life

In terms of the meaning of QOL, most Chinese cervical cancer survivors defined it as being in good health and free of disease. Other Chinese cervical cancer survivors take QOL as being happy with the quality of one's work and of one's interpersonal/social relationships with colleagues and society. These findings are similar to those of previous studies taking place in Taiwan and Hong Kong: Chinese cancer survivors in these studies also viewed "normal living", a good working life, happiness, material resources and support from their families as essential indicators of QOL (Yang & Yin, 1999; Molassiotis et al., 2000).

Culture has been recognized as one of the most powerful factors influencing health-related attitudes and beliefs (Spector, 2004). Beliefs and values related to family are as strong as religious belief for Chinese (Chen, 2001). That is the reason that most Chinese cervical cancer survivors took family support, the quality of family relationship or with a harmonious atmosphere of family, and the whole family members' well-being as an important aspect of their QOL. Compared with the definitions of QOL by Western cancer survivors, the concept of QOL was defined as being independent, reclaiming life, psychological well-being or social relationships (Dow et al., 1999). In consequence, the emphasis on collectivity (family or family members as a whole) versus independence was determined different perceptions of QOL between Chinese and Western cancer survivors.

7.1.2 The impact of cervical cancer survivorship on Chinese women's QOL

For the impact of cervical cancer survivorship on women's QOL, there were consistent findings with research in Western countries (Ashing-Giwa et al., 2004; Distefano et al., 2008; Greimel et al., 2009), Chinese women in this study reported numerous treatment side-effects: poor sleep quality, vomit, premature menopause symptoms, anxiety, depression, reduced social function and unsatisfied sex life. In addition, there were similar findings identified in this study as in Western countries (Akyuz et al., 2008; Hodgkinson et al., 2007; Clemmens et al., 2008). Chinese women in this study shared their positive changes since cancer diagnosis: more positive life outlook, more appreciation of life, feeling cancer experience as rebirth and more treasuring life.

Other psychological impacts of cancer were including feeling guilty and reduced self-esteem. Social rejection against cervical cancer survivors is common in China, as cervical cancer is viewed as a 'dirty disease', and is labelled as one of sexually transmitted disease related to early sexual activity, multiple sex partners (Lai et al., 2009), which may result in women having long-term feelings of self-blame and impact their emotional well-being (Chan et al., 2001).

Coping strategies are thought to play an important role in managing the physical and psychological sequelae associated with a cancer diagnosis and treatment (Costanzo et al., 2006). When comparing with the coping strategies used by women in the western countries, there were differences existed between women in China and Western countries. In Western counties such as in the USA, 'praying' is commonly used coping strategies for female cancer survivors after treatment (Lauver et al., 2007). Chinese cervical cancer survivors in this study were most often coping with their disease by family support and caring.

7.1.3 Sexuality issues and quality of life among Chinese cervical cancer survivors

Although sexual issues are not openly discussed and viewed as a cultural taboo in Chinese communities (Khoo, 2009), unexpected findings from this study were that some Chinese cervical cancer survivors defined the importance of sex life and the harmony of sexual relationship with husband as one of major indicators of their QOL. This is possibly because there is high rate of sexual morbidity prevalent in cervical cancer survivors. About 58% of women who were sexually active before cancer refrained completely from sexual intercourse after the diagnosis (Khoo, 2009). In China, one study found that 60% Chinese women after diagnosis of cervical cancer reported a complete void of sexual activity (Liu et al., 2006).

In this study, 13 out of 35 informants reported a complete ceasing of sexual activities after cancer treatment or since the diagnosis of cervical cancer, 8 Chinese women indicated that there were significant changes in their sexual life including the reduced frequency and quality of sexual activities. The reasons for not resuming sexual activities were including treatment side-effects such as radiation therapy result in

dryness of vaginal, no husband/sexual partners, husband having poor health conditions, feeling tied, lack of interest and perceived old age. Additionally, Chinese women and their husband/sexual partners hold misconceptions: cancer is contagious and can be transmitted through sexual activities, sexual intercourse may weaken the potency of therapeutic drugs or treatment, and fearing cancer will recur if continuing to have sex after cancer treatment (Liu et al., 2006; Molassiotis et al., 2000). These findings indicate a need for Chinese nurses and other healthcare providers to help cervical cancer survivors dispel relevant misconceptions about sexuality and cancer.

7.1.4 Sexuality issues among Chinese gynecologic cancer survivors

Body image

This study set out to describe sexuality issues among Chinese gynecologic cancer survivors. Researchers increasingly indicated the importance of assessing body image in cancer patients (Hopwood et al., 2001). Previous evidence shows that poor self-image caused by changes in weight or disfiguring surgery may contribute to sexual problems after gynecologic cancer (Bodurka & Sun, 2006). However, in this study around 60-70% of Chinese women felt reasonably attractive, and around 50% felt sexually appealing. In the absence of comprehensive evidence base, future research is needed to explore why most participants reported positive feelings of body image even with severely compromised sexual function. One possible reason is that most participants have recently completed their initial treatment, so that discussing sexuality concerns such as body image may come down a list of priorities that rightly place afraid of recurrence and survival in women's minds (White 2008).

Role and sexual relationships

Role and sexual relationship issues remain a problem for gynecologic cancer survivors. In this study, 69.3% of women reported that cancer has negatively impacted the overall quality of sexuality relationship. Although more than half of participants reported cancer has not impact the role as a mother, 62.9% indicated that cancer had moderately to severely impacted on their roles as sexual partners. In terms of role identity issues, 64.7% reported a moderate negative impact and 13.5% reported a severe impact on reduced sense of femininity. A study on women with ovarian cancer also demonstrated that the cancer can affect women's self-perception as sexually desirable (Stead et al., 2007). A qualitative study among women with

cervical and endometrial cancer highlighted that a reduced sense of femininity and feeling less a woman have negatively influenced women not to resume sexual activity (Juraskova et al., 2003). In this study, 12.2% of participants indicated that cancer has severe impact on their overall quality of sexual relationship. Lindau et al. (2007) suggest that with an understanding of survivors how to maintain sexual partnerships may help healthcare providers and survivors better understand the role of sexual relationships in coping with cancer, and maximizing survival and quality of life.

Sexual dysfunctions

Sexual dysfunction was a consistent concern for Chinese gynecologic cancer survivors. Altered sexual functioning is the most compromised quality of life issue after treatment for gynecologic cancer (Audette & Waterman, 2010). Previous studies have shown that treatment for cervical cancer has a potential negative impact on patients' sexuality, such as reduced sexual interest/desire, lack of lubrication, dyspareunia, reduced orgasm frequency, vaginal changes, and dissatisfaction with their sex life (Jensen et al., 2003; 2004). In another investigation on a sample of ovarian cancer survivors, 47% evidenced a lack of desire for sexual intercourse following treatment, 62% reported pain, and 80% of the research participants experienced vaginal dryness during sexual intercourse (Carmack Taylor et al., 2004). In this study, 77.5% of Chinese women reported little or no sexual desire, 52.6% reported pain during sexual intercourse, and 73.7% indicating difficulty in reaching orgasm. In order to address women's sexual dysfunction, lack of sexual desire, arousal disorder, vaginal dryness, pain during sexual intercourse and orgasmic problems should be taken into account as a whole.

Issues of sexual activity

The rate of sexual inactivity was relatively high in this study, as most women (n = 110) had not engaged sexual intercourse in the previous month. Approximately 70% of women indicated dissatisfied with the frequency of sexual intercourse. Reasons for not engaging in sexual intercourse included fear of cancer recurrence, sex weakening the potency of treatment effects, ceasing sexual intercourse for disease recovery, feeling too tied to have sex, and lack of sexual interest. The fear of sex causing a recurrence of cancer may be due to Chinese women's misconceptions. Similar findings were reported in a study of Hong Kong Chinese women, whose spouses

viewed gynecologic cancer as probably resulting from excessive sexual activity weakening the female body (Molassitotis et al., 2000). Reducing or ceasing sexual activity for disease recovery may be related to Chinese culture. Taoist sexual beliefs about the regulation of sexual activities to preserve health suggest that Chinese gynecologic cancer survivors and their partners reduce or cease sexual activities after cancer treatment in order to facilitate the recovery of a woman's health (Tang et al., 1996).

7.1.5 Pre-post cancer comparison of sexuality issues among Chinese women

When looking at predictors of negative changes of women's sexuality after cancer, this study found that age (50 or above) was a significant predictor of a reduction in the frequency of sexual activity. Other studies on ovarian cancer survivors found that women were more likely to be sexually active if they were 56 or under (Carmack Taylor et al., 2004). As for sexuality in relation to religious and cultural norms, older women are more sexually conservative than younger people, regardless of education levels (Le Gall et al., 2002). Time since completing initial treatment (within half an year) adversely predicted the frequency of sexual activity. This indicated that the more time that lapsed since the initial treatment, the more likely the women were to resume sexual activity. Based on an investigation in ovarian cancer survivors, sexual activity was also predicted by a longer time elapsing since active treatment or initial diagnosis (Carmack Taylor et al., 2004).

Types of treatment (ever having received radiation therapy) were significant predictors of vagina dryness and pain during sexual intercourse. It was confirmed that women who had received radiotherapy had more symptoms of vaginal dryness and dyspareunia than those who had not. In terms of the overall quality of sexual relationship, those with higher education levels reported fewer negative changes in their sexual relationships than women with lower education levels. There is other evidence that higher education is associated with greater sexual functioning or satisfaction (Carmack Taylor et al., 2004). The possible reasons is that women with higher education levels may have good financial security, insurance and more social networks, which have known to be effective in increasing overall life satisfaction.

7.1.6 Chinese nurses' attitudes and beliefs regarding patients' sexuality concerns

The present study set out to describe Chinese nurses' attitudes to and practice of addressing sexuality concerns with gynecologic cancer patients. The results of this study reveal that Chinese nurses had a total mean SABS of 44.94 (SD 8.12), indicating higher levels of barriers to addressing patients' sexuality issues in practice than either Swedish nurses (with total mean SABS of 40.7 SD 7.8) (Saunamaki et al., 2010) or American nurses (with total mean SABS of 37.48 SD 8.19) (Magnan & Reynolds, 2006). This indicates that Chinese nurses have higher levels of barriers to discussing sexuality concerns with their patients than American and Swedish nurses.

Specifically, a majority of Chinese nurses held the attitude that 'sexuality is too private an issue to discuss with patients', and that 'most hospitalized patients are too sick to be interested in sexuality'. The majority of nurses did not 'make time to discuss sexual concerns with patients', were 'less comfortable talking about sexual issues with patients than other nurses', and were 'not confident in [their] own ability to address patients' sexual concerns'. It is because of these attitude and beliefs that well over half of the Chinese nurses surveyed believed that 'sexuality should be discussed only if initiated by patients' and that 'they would advise patients to discuss sexual concerns with their physicians'.

7.1.7 Common facilitators and barriers influencing sexuality issue discussion in nursing practice

The Chinese nurses generally agreed that the key facilitating factors for nursing practice related to sexuality concerns are 'good nurse-patient relationship', 'good communication skills', 'availability of a private environment', and 'nurses' possessing sound sexuality knowledge'. Besides having the misconception that 'women with cancer have more things to be concerned about than having sex', Chinese nurses agreed that 'staff shortages resulting in limited time, energy and resources' are the key barriers to nursing practice related to sexuality concerns.

In practice, most of these Chinese nurses 'never, rarely or seldom' made 'referrals to sexuality counseling', 'listened to or answered patients' sexuality concerns', 'told patients about possible side-effects of cancer treatments', 'provided patients with information about sexuality concerns', 'discussed the risk of early/premature

menopause for women of childbearing age', or 'discussed the impact of body image changes on sexuality'. In a study conducted in the UK, interviews were conducted with 43 physicians and nurses who regularly worked with ovarian cancer patients; it was found that 98% of these healthcare providers felt that sexual issues should be discussed with patients, but only 21% reported actually doing so (Stead et al., 2003). In this study, less than 10% of Chinese nurses frequently addressed the sexuality concerns of their patients in practice, although more than half agreed with 'discussing sexuality being essential to patients' health outcomes'.

Both personal and environmental factors accounted for Chinese nurses' not providing sexuality care for gynecologic cancer patients. Examining the relationships between the total nursing practice scores and the nurses' demographics revealed that nurses with longer work experience and in higher positions had higher total nursing practice scores ($p = 0.001$, $p < 0.001$). This indicates that these nurses were more likely to address the sexuality concerns of gynecologic cancer patients than younger nurses with less work experience and in lower positions. It is understandable that the maturity of nurses has implications for their readiness to discuss sexuality concerns with their patients.

7.1.8 Predicting factors relating to the sexuality care in nursing practice

Regression analysis revealed that married nurses were more likely than single nurses to address sexuality issues with their patients. A systematic review identified marital status as one of the potential influencing factors in providing sexual health care in the context of cancer (Kotronoulas et al., 2009). Additionally, the results of this study also show that Chinese nurses working in general hospitals were more likely to discuss sexuality issues than those in tumor hospitals. Compared with nurses in general hospitals (caring not just for gynecologic cancer but also for other gynecologic disease patients), nurses from tumor hospitals provided direct cancer care for gynecologic cancer patients, so that they might be more often influenced by myths related to cancer, such as 'people with cancer have more things to be concerned about than having sex' (Quinn, 2003). These myths about sexuality have predominated in the field of cancer, as sex education is often lacking or discouraged in certain societies, and cultural traditions may encourage misinformation, leading to anxiety and fear about sex (Fisher et al., 2003).

Chinese nurses viewing sexuality as too private and sensitive an issue to discuss with their patients was a significant factor affecting sexuality care in practice. Sexuality-related care has traditionally been a taboo in clinical practice (Burd et al., 2006), especially in China, where more than 3000 years of sexual suppression has resulted in a culture of sexual conservativeness (Zeng, 2004). It is therefore not surprising to find that Chinese nurses felt uncomfortable talking about sexuality issues with their patients. Despite this specific cultural background, Chinese nurses need to be made aware that sexuality-related care is an important part of holistic nursing care. Another significant predictor was that when patients asked a sex-related question, nurses advised them to discuss the matter with their physicians. Although hospital settings in mainland China are gradually shifting from a strictly medical model of care to a holistic approach and a patient-centered care model, current nursing practice still follows a medical-dominated care model. Thus, with medical dominance Chinese nurses may lack autonomy and feel less confident in addressing these sensitive care issues.

The availability of a private environment was one of the facilitators enabling nurses to discuss sexuality issues with patients in practice. Other studies conducted in the UK and Greece also reported that nurses working in clinical settings cited lack of privacy as one of their reasons for not discussing sexuality with patients in practice (Lewis & Bor, 1994; Nakopoulou et al., 2009). Due to the fact that sexuality is such a sensitive and confidential issue, Chinese nurses should be aware of the need to provide an environment conducive to discussing sexuality issues with patients.

The prejudices of ‘people with cancer having more things to be concerned about than having sex’ and ‘sexuality representing a low priority issue at diagnosis and during treatment of cancer’ were significant predictors of sexuality care in nursing practice. Other studies also revealed that viewing sexuality as a low priority among cancer patients may be due to oncology nurses’ prejudices regarding sexuality in cancer (e.g. Stead et al., 2003). It is understandable that in the face of life-threatening disease, sex may not be the top priority of cancer patients, but it does not mean that they totally lose interest in it. A study in China that examined the perspectives of cancer patients found that most gynecologic cancer patients (78.8%) indicated that sexual activity

was an important part of their life (Zeng et al., in press-b). Other studies have also reported that sexuality is not only important but identified as being of equal importance to other quality of life issues (Ananth et al., 2003; Southard & Keller, 2009). In consequence, there is a need to dispel Chinese nurses' prejudices about sexuality issues among cancer patients.

Factors relating to nurses, such as feeling discomfort or embarrassment, limited knowledge, lack of relevant experience, being afraid of violating patients' privacy and inadequate education preparation were also significant predictors of sexuality care in practice. Similar findings show that oncology nurses failed to respond to patients' sexual concerns due to limited sexual knowledge and inadequate training (Kotronoulas et al., 2009; Stilos et al., 2008). In another study, Greek nurses indicated that they felt comfortable talking about sexual health issues when they had a good nurse-patient relationship (Nakopoulou et al., 2009). Another study in the UK also found that building relationships between healthcare providers and patients is essential in facilitating discussion about sensitive topics such as sexuality issues (Gott et al., 2004). Therefore, building a good nurse-patient relationship and providing relevant training for nurses may be helpful in reducing nurses' problems in addressing patents' sexuality concerns.

7.2 Study limitations

In the first study stage, there was just one single tumor hospital involved as the research setting, thus making it difficult to establish the transferability of study findings. Other limitations were only using written narratives as means of data collections. Written narratives may also be lack of interactions and spontaneity as face-to-face interviews, although the informants may be more like to share sensitive issues such as women's sexual health by written narratives due to less interaction pressure. Further research needs to provide diverse means of data collection to compensate this limitation.

In the second study stage, possibly because of the sensitive nature of the research topic, the final sample size was relatively small. While much larger numbers of subjects may be required for the generalizability of study findings, these findings may serve as preliminary data to refine this sexuality scale for better assessing the

sexuality concerns of Chinese gynecologic cancer survivors. The lack of a control group in this study stage precludes us from drawing definitive conclusions about the extent/degree of changes in sexuality among gynecologic cancer survivors.

In the third study stage, although this study stage provides important information on a previously unexplored issue in China, there are some limitations. The relatively small sample size and the use of a convenience sample limit the generalizability of the study findings. Further research is needed, using a larger sample size across oncology care settings nationwide. In addition, conducting research related to sexuality may be sensitive. Study findings were based on answers from a self-reported questionnaire. It is therefore difficult to exclude the possibility of socially desirable responses being given for this sensitive research topic. However, any alternative method would be equally likely to be affected by this problem. Finally, due to a dearth of similar research conducted in China, in this study most research findings were discussed and compared with study findings from Western culture countries. Because of cultural differences, Western study results and practices could not be generalized to Chinese women.

7.5 Summary

The chapter provides a discussion of study findings. On one hand, this chapter discussed relevant issues about the QOL and sexuality among Chinese gynecologic cancer survivors. On the other hand, this chapter discussed issues about Chinese nurses' attitudes and beliefs regarding patients' sexuality concerns and relevant predicting factors relating to the sexuality care in nursing practice.

Chapter 8
Implications and Conclusion

8.1 Implications

8.1.1 Implications for nursing education

Chinese nurses felt uncomfortable and less confident, reporting limited knowledge and inadequate education preparation as significant barriers to addressing sexuality issues with patients. This may be because existing nursing education in China offers minimal training related to sexuality issues. As lack of training was cited as the main reason for nurses not addressing the sexuality concerns of cancer patients (Hautamaki et al., 2007), more training related to sexuality issues is needed for Chinese nurses in the nursing curricula or continuing education programs. The same can be done through continuing education for professional nurses. Patient education written materials can be developed which may help nurses to feel more comfortable in sharing with patients on their sexuality concerns. Guthrie (1999) emphasized that introducing sexuality knowledge as part of the nursing curriculum is not enough. Nursing education should equip nurses with the communication skills necessary to integrate such knowledge into practice (Guthrie, 1999). In particular, there is a need to provide real role models to discuss sexuality issues with patients (Hautamaki et al., 2007; Algier & Kav, 2008).

A previous study has identified good nurse-patient relationship and possessing good communication skills as facilitating factors for nurses in addressing patients' sexuality concerns (Zeng et al., 2011). Zeng et al. further reported that inadequate preparation of training was one of barriers for Chinese nurses address gynecologic cancer patients' sexuality concerns in practice. Other studies also indicated that a lack of training in communication skills for physicians resulted in difficulties dealing with patients' sexual problems (Tsimtsiou et al., 2006). A lack of communication between healthcare professionals and patients about sexual issues can prolong patients' sexual difficulties (Stead et al., 2007). Therefore, there is a need for medical/nursing education to provide relevant training in discussing sexuality issues with patients, as training in nurse/physician-patient communication skills can enhance the healthcare providers' ability to handle even uncomfortable situations associated with sexuality issues. Additionally, training may lead healthcare providers to the adoption of a holistic approach for recognizing the patient's values, preferences, and special needs to establish an effective clinician-patient relationship (Tsimtsiou et al., 2006).

8.1.2 Implications for nursing practice

Women with gynecological cancer may have numerous sexuality concerns, therefore it is important for nurses and other healthcare providers in China to facilitate sexuality concern discussion. In practice, Chinese nurses rarely address the sexuality issues of gynecological cancer patients. In the atmosphere of the medical-dominated care model, Chinese nurses always advise patients to discuss sexuality-related issues with their physicians. Hence, the multi-disciplinary team is important in providing comprehensive support for women's sexuality concerns by collaborating with each other. Nurses should also refer patients to specialist sexual counseling services by certificated sexual therapists if the problem is beyond the remit of nurses (Wilmoth, 2006).

In addition, some facilitators in addressing the sexuality concerns of women with gynecological cancer included adding sexuality into routine nursing care and providing a private environment. These strategies were also recommended by existing literature regarding considerations when addressing sexuality in cancer care (e.g. Hordern & Currow, 2003). Other strategies included addressing the myths and prejudices (e.g. cancer is contagious), being nonjudgmental, indicating a willing attitude to talk about sexuality issues, and providing an environment conducive to discussing sexuality issues (Hordern & Currow, 2003; Cagle & Bolte, 2009).

Taking into account the high rates of sexual dysfunction and sexual inactivity, and given the fact that 78.8% of gynecologic cancer survivors in this study thought of issues related to sex as an important part of their life, these is a clear need to integrate sexuality into routine clinical care (Levin et al., 2010). This does not seem to be the case in clinical practice. Interviews with 43 physicians and nurses regularly treating women with ovarian cancer found that although 98% of providers felt that sexual issues should be discussed with patients, only 21% reported actually doing so (Stead et al., 2003). Other studies show that nurses working in gynecologic cancer unit believe that sexuality is an important health outcome of cancer patients and have lower levels of barriers in addressing patients' sexuality concerns than nurses working in medical/surgical oncology units (Zeng et al., 2010b). However, another study reported that in daily clinical practice, as many as 40% of Chinese nurses never addressed patients' sexuality concerns (Zeng et al., 2011).

Although increasing numbers of articles related to sexuality are being published, there is still no clear practice recommendation related to assisting healthcare providers in addressing gynecologic cancer survivors' sexuality concerns (Audette & Waterman, 2010). Despite the lack of guidelines, the most important step for healthcare providers is to initiate a conversation on sexuality issues by direct inquiry. This will allow patients to realize that it is acceptable to raise any sexuality concern and convey healthcare providers' comfort with the topic (Bodurka & Sun, 2006). It should also be noted though that women do not always require intensive support; they often only need reassurance that sexual problems are normal, and permission to ask about sexual difficulties (Stead et al., 2007).

8.1.3 Implications for nursing research

This study found that most Chinese nurses did not make time to address sexuality concerns of gynecologic cancer patients, thus future studies need to explore specific factors such as religious beliefs, environments (rural versus urban), and culture influencing the degree to which nurses incorporate sexuality care into their practice. Comparison studies could be conducted to explore if the provision of education pertaining to sexuality can make the differences between nurses who received the education and those who did not, and if patient education written materials can help nurses to be more comfortable in sharing with cancer patients on sexuality concerns. All these studies are needed in order to gain a better understanding of how Chinese nurses can be helped to increase their skill and comfort in providing sexual information to cancer patients.

In order to determine the extent/degree of sexuality concerns among Chinese gynecologic cancer survivors, future research should incorporate appropriate comparison groups to further explore this issue. Additionally, future interventions studies should optimize positive outcomes (e.g. changes of life outlooks and better family relationships) and minimize the negative QOL outcomes (e.g. a burden to the family, financial concerns, psychological concerns) for Chinese cervical cancer survivors.

8.2 Highlights of key findings

The first study stage found that Chinese cervical cancer survivors have ongoing QOL concerns regarding the experience of living beyond the diagnosis and treatment for their cancer. Although sexuality issues are not openly discussed in Chinese communities and viewed as a cultural taboo, some Chinese cervical cancer survivors defined the importance of sexual activity and the harmony of sexual relationship with husband as major indicators of their QOL.

In the second study stage, study findings provided important data regarding the sexuality issues among Chinese gynecologic cancer survivors. Chinese women with gynecologic cancer face numerous challenges of their sexuality. Significant predictors of negative sexuality changes included women over 50 years old, received treatment of radiotherapy, completed initial treatment within half a year, and with lower education background.

In the third study stage, study results indicated that Chinese nurses considered sexuality as too private an issue to discuss with patients, and assumed that sexuality concerns were not a priority issues for gynecologic cancer patients. Chinese nurses were less likely to make time to discuss sexuality issues with patients. Nurses' marital status, type of hospital working in, their personal misconceptions and prejudices about sexuality and cancer, lack of relevant experience, limited knowledge and feeling of embarrassment prevent nurses to address the sexuality concerns of gynecologic cancer patients.

8.3 Conclusion

This study demonstrated the importance of considering the impact of cervical cancer survivorship on Chinese women's QOL. Chinese gynecologic cancer survivors suffered from various sexuality concerns. Addressing sexuality concerns of this target population should offer relevant psychosexual education interventions to dispel these women and their partners' related fears (e.g. partners' fear of contracting cancer by sex) and misconceptions (e.g. sex causing cancer recurrence, sex impeding disease recovery). Chinese nurses assumed sexuality concerns being not a priority issue for gynecologic cancer patients, and were less likely to make time to discuss sexuality issues with patients. There is a need to increase Chinese nurses' awareness of their

roles and the need to equip themselves with relevant skills in providing sexuality care for patients.

References

References

Abraham M (1999) Sexual abuse in South Asian immigrant marriage. *Violence against Women,* 5 (6), 591-618.

Akyuz A, Guvenc G, Ustunsoz A, Kaya T (2008) Living with gynecologic cancer: Experience of women and their partners. *Journal of Nursing Scholarship,* 40 (3), 241-247.

Algier L, Kav S (2008) Nurses' approach to sexuality-related issues in patients receiving cancer treatment. *Turkish Journal of Cancer,* 38 (3), 135-141.

American National Cancer Institute Office of Cancer Survivorship (2006) About Cancer Survivorship Research: Survivorship Definitions. Rockville: U.S. Available at http://cancercontrol.cancer.gov/ocs/definitions.html (accessed on 2 November 2008).

Ananth H, Jones L, King M, Tookman A (2003) The impact of cancer on sexual function: a controlled study. *Palliative Medicine,* 17 (2), 202-205.

Anderson B, Lutgendorf S (1997) Quality of life in gynecological cancer survivors. *CA: A Cancer Journal for Clinicians,* 47 (4), 218-225.

Armstrong DK (2002) Relapsed ovarian cancer: challenges and management strategies for a chronic disease. *Oncologist,* 7 (suppl 5), 20-28.

Ashing-Giwa KT, Kagawa-Singer M, Padilla GV, Tejero JS, Hsiao E, Chhabra R, Martinez L, Tucker MB (2004) The impact of cervical cancer and dysplasia: A qualitative, multiethnic study. *Psycho-Oncology,* 13 (10), 709-728.

Ashing-Giwa KT (2008) Enhancing physical well-being and overall quality of life among underserved latina-american cervical cancer survivors: Feasibility study. *Journal of Cancer Survivorship,* 2 (3), 215-223.

Audette C, Waterman J (2010) The sexual health of women after gynecologic malignancy. *Journal of Midwifery and Women's Health*, 55 (4), 357-362.

Bancroft J (2009) *Human Sexuality and its Problems* (3rd ed.) London: Elsevier.

Barton DP (2003) The prevention and management of treatment related morbidity in vulval cancer [Review]. *Best Practice & Research Clinical Obstetrics and Gynaecology,* 21 (2), 309-320.

Bodurka DC, Sun CC (2006) Sexual function after gynecologic cancer. *Obstetrics and Gynecology Clinics of North America,* 33 (4), 621-630.

Bradley S, Rose S, Lutgendorf S, Costanzo E, Anderson B (2006) Quality of life and mental health in cervical and endometrial cancer survivors. *Gynecologic Oncology,* 100 (3), 479-486.

Brown TA, Cash TF, Mikulka PJ (1990) Attitudinal body-image assessment: Factor analysis of the body-self relations questionnaire. *Journal of Personality Assessment*, 55 (1-2), 135-144.

Burd ID, Nevadunsky N, Bachman G (2006) Impact of physician gender on sexual history taking in a multispecialty practice. *Journal of Sexual Medicine,* 3 (2), 194-200.

Burnard P (1991) A method of analyzing interview transcript in qualitative research. *Nurse Education Today*, 11 (6), 461-466.

Byers ES (1998) Sexual Activity Questionnaire. In CM. Davis, WL, Yarber, R. Bauserman, G. Schreer, SL. Davis (Eds.). *Handbook of Sexuality-related Measures.* Thousand Oaks: Sage.

Cagle JG, Bolte S (2009) Sexuality and life-threatening illness: implications for social work and palliative care. *Health & Social Work,* 34 (3), 223-233.

Calman KC (1987) Definitions and dimensions of quality of life. In N. Aaronson, J. Beckman, & R. Zittoun (Eds.) *The Quality of Life of Cancer Patients.* New York: Raven Press.

Caplan KC (1984) The quality of life in cancer patients-an hypothesis. *Journal of Medical Ethics*, 10 (3), 124-127.

Carmack Taylor CL, Basen-Engquist K, Shinn EH, Bodurka DC (2004) Predictors of sexual functioning in ovarian cancer patients. *Journal of Clinical Oncology,* 22 (5), 881-889.

Chan YM, Ngan HYS, Li BYG, Yip AMW, Ng TY, Lee PWH, et al. (2001) A longitudinal study on quality of life after gynaecologic cancer treatment. *Gynaecologic Oncology,* 83 (1), 10-19.

China Cancer Database (2004) The epidemiology of cervical cancer. Beijing China. http://cancernet.cicams.ac.cn/index.php?option=content&task=view&id=23&Itemid=40 Accessed on 2/11/2008

Chen YC (2001) Chinese values, health and nursing. *Journal of Advanced Nursing*, 36 (2), 270-273.

Clemmens DA, Knafl K, Lev EL, McCorkle R (2008) Cervical cancer: patterns of long-term survival. *Oncology Nursing Forum,* 35(6), 897-903.

Costanzo ES, Lutgendorf S, Rothrock NE, Anderson B (2006) Coping and quality of life among women extensively treated for gynecologic cancer. *Psycho-Oncology, 15*(2), 132-142.

Creswell JW (2007) *Qualitative Inquiry and Research Design: Choosing among Five Approaches.* California: Sage.

Distefano M, Riccardi S, Capelli G, Costantini B, Petrillo M, Ricci C, et al. (2008) Quality of life and psychological distress in locally advanced cervical cancer patients administered pre-operative chemoradiotherapy. *Gynecologic Oncology*, 111 (1), 144-150.

Dow KH, Ferrell BR, Haberman MR, Eaton L (1999) The meaning of quality of life in cancer survivorship. *Oncology Nursing Forum*, 26 (3), 519-528.

Dubos R (1976) The state of health and the quality of life. *Western Journal of Medicine*, 125 (1), 8-9.

Fayers PM, Machin D (2007) *Quality of Life: the Assessment, Analysis and Interpretation of Patient-reported Outcomes.* (2nd ed.). London: John Wiley & Sons.

Ferrans CE (2005) Quality of life as an outcome of cancer care. In C.H. Yarbo, M.H. Frogge, & M. Goodman (Eds.), *Cancer Nursing: Principles and Practice* (6th ed., pp. 183-197). Sudbury: Jones and Bartlett Publishers.

Ferrell BR, Grant MM, Funk B, Otis-Green S, Garcia N (1997) Quality of life in breast cancer survivors as identified by focus groups. *Psycho-Oncology*, 6 (1): 13-23.

Feuerstein M (2007) Defining cancer survivorship. *Journal of Cancer Survivorship*, 1 (1), 5-7.

Fisher JA, Bowman M, Thomas T (2003) Issues for South Asian Indian patients surrounding sexuality, fertility, and childbirth in the U.S. health system. *Journal of the American Board of Family Practice*, 16 (2), 151-155.

Frumovitz M, Sun CC, Schover LR, Munsell MF, Jhingran A, Wharton JT, et al. (2005) Quality of life and sexual functioning in cervical cancer survivors. *Journal of Clinical Oncology*, 23 (30), 7428-7436.

Gotheridge SM, Dresner N (2002) Psychological adjustment to gynecologic cancer. *Primacy Care Update for OB/GYNS*, 9 (2), 80-84.

Gott M, Hinchliff S, Galena E (2004) General practitioner attitudes to discussing sexual health issues with older people. *Social Science & Medicine*, 58 (11), 2093-2103.

Greimel ER, Winter R, Kapp KS, Haas J (2009) Quality of life and sexual functioning after cervical cancer treatment: a long-term follow-up study. *Psycho-Oncology*, 18 (5), 476-482.

Guthrie C (1999) Nurses' perceptions of sexuality relating to patient care. *Journal of Clinical Nursing*, 8(3), 313-321.

Haboubi NHJ, Lincoln N (2003) Views of health professionals on discussing sexual issues with patients. *Disability Rehabilitation*, 25 (6), 291-296.

Hamilton RJ, Bowers BJ (2006) Internet recruitment and e-mail interviews in

qualitative studies. *Qualitative Health Research,* 16 (6), 821-835.

Hao YT, Wan CH (2000) The research design and implementation of investigating quality of life. In Q.K. Fang (Ed.) *The Measurement and Application of Quality of Life.* Beijing: Beijing Medical University Press. P79-89.

Hautamaki K, Miettinen M, Kellokumpu-Lehtinen P, Aalto P, Lehto J (2007) Opening communication with cancer patients about sexuality-related issues. *Cancer Nursing,* 30 (5), 399-404.

Higgins A, Barker P, Begley CM (2006) Sexuality: The challenges to espoused holistic care. *International Journal of Nursing Practice,* 12 (6), 345-351.

Hodgkinson K, Butow P, Fuchs A, Hunt GE, Stenlake A, Hobbs KM, et al. (2007) Long-term survival from gynecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. *Gynecologic Oncology,* 104 (2), 381-389.

Holloway I, Wheeler S (2002) *Qualitative Research in Nursing* (2nd ed.). Oxford: Blackwell Science.

Hopwood P, Fletcher I, Lee A, Ghazal SA (2001) A body image scale for use with cancer patients. *European Journal of Cancer,* 37 (2), 189-197.

Hordern AJ, Currow DC (2003) A patient-centered approach to sexuality in the face of life-limiting illness. *Medical Journal of Australia,* 179 (Suppl.1), 8-11.

Hunt N, McHale S (2007) A practical guide to the e-mail interview. *Qualitative Health Research,* 17 (10), 1415-1421.

Jeffery DD, Tzeng JP, Keefe FJ, Porter LS, Hahn EA, Flynn KE, et al. (2009) Initial report of the cancer patient-reported outcomes measurement information system (PROMIS) sexual function committee. *Cancer,* 115 (6), 1142-53.

Jensen PT, Groenvold M, Klee MC, Thranov I, Petersen MA, Machin D (2003) Longitudinal study of sexual function and vaginal changes after radiotherapy for cervical cancer. *International Journal Radiation Oncology Biology Physics,* 56 (4), 937-949.

Jensen PT, Groenvold M, Klee MC, Thranov I, Petersen MA, Machin D (2004) Early-stage cervical carcinoma, radical hysterectomy, and sexual function. *Cancer,* 100 (1), 97-106.

Juraskova I, Butow P, Robertson R, Sharpe L, McLeod C, Hacker N (2003) Post-treatment sexual adjustment following cervical and endometrial cancer: a qualitative insight. *Psycho-Oncology,* 12 (3), 267-279.

Katz A (2005) Do ask, do tell: Why do so many nurses avoid the topic of sexuality? *American Journal of Nursing,* 105 (7), 66-68.

Khoo SB (2009) Impact of cancer on psychosexuality: Cultural perspectives of Asian women. *International Journal of Nursing Practice,* 15 (6), 481-488.

Kong SKF, Wu LH, Loke AY (2009) Nursing students' knowledge, attitude and readiness to work for clients with sexual health concerns. *Journal of Clinical Nursing,* 18 (16), 2372-2382.

Korfage IJ, Essink-Bot M, Mols F, van de Poll-Franse L, Kruitwagen R, van Ballegooijen M (2009) Health-related quality of life in cervical cancer survivors: A population-based survey. *International Journal of Radiation Oncology Biology Physics,* 73 (5), 1501-1509.

Kotronoulas G, Papadopoulou C, Patiraki E (2009) Nurses' knowledge, attitudes, and practices regarding provision of sexual health care in patients with cancer: critical review of the evidence. *Support Care in Cancer,* 17 (5), 479-501.

Kozier B, Erb G, Berman AJ, Snyder S (2004) *Fundamentals of Nursing: Concepts, Process and Practice.* 7th ed. Upper Saddle River, N.J.: Prentice Hall Health.

Krebs LU (2008) Sexual assessment in cancer care: Concepts, methods and strategies for success. *Seminars in Oncology Nursing,* 24 (2), 80-90.

Lai BPY, Tang CS, Chung TKH (2009) Age-specific correlates of quality of life in Chinese women with cervical cancer. *Supportive Care in Cancer,* 17 (3), 271-278.

Lauver DR, Connolly-Nelson K, Vang P (2007) Stressors and coping strategies among female cancer survivors after treatments. *Cancer Nursing,* 30 (2), 101-111.

Le Gall A, Mullet E, Shafighi SR (2002) Age, religious beliefs, and sexual attitudes. *Journal of Sex Research,* 39 (3), 22-44.

Leigh SA (1996) Defining our destiny. In: B. Hoffman (Ed.) *A Cancer Survivor's Almanac: Charting the Journey* (pp. 261-271). Minneapolis: Chronimed Publishing.

Leininger M (1994) Evaluation criteria and critique of qualitative research studies. In JM. Morse (Ed.) *Critical Issues in Qualitative Research Methods*. Thousand Oaks: Sage.

Lenahan PM (2004) Sexual Health and Chronic Illness. *Clinics in Family Practice,* 6 (4), 955-973.

Levin AO, Carpenter KM, Fowler JM, Brothers BM, Andersen BL, Maxwell L (2010) Sexual morbidity associated with poorer psychological adjustment among gynecologic cancer survivors. *International Journal of Gynecologic Cancer,* 20 (3), 461-470.

Lewis SL, Bor R (1994) Nurses' knowledge of and attitudes towards sexuality and the relationship of these with nursing practice. *Journal of Advanced Nursing,* 20 (2), 251-259.

Lincoln YS, Guba E (1985) *Naturalistic Inquiry*. Beverly Hills: Sage.

Lindau ST, Gavrilova N, Anderson D (2007) Sexual morbidity in very long term survivors of vaginal and cervical cancer: a comparison to national norms. *Gynecologic Oncology*, 106 (2), 413-418.

Liu Z, Kong W, Liu T, Li J (2008) The analysis of quality of life in patients with cervical cancer. *China Practical Journal of Gynecology and Obstetrics,* 24 (7), 529-531. [in Chinese]

Liu Z, Wang J, Wang GQ, Luo W (2006) Investigation of the quality of life after radiotherapy of cervical cancer patients. *Modern Oncology* 14, 1180-1181. [in Chinese]

Lutgendorf SK, Anderson B, Ullrich P, Johnsen EL, Buller RE, Sood AK, Sorosky JI, Ritchie J (2002) Quality of life and mood in women with gynecologic cancer: a one year prospective study. *Cancer,* 94 (1), 131-40.

Magnan MA, Norris DM (2008) Nursing students' perceptions of barriers to addressing patient sexuality concerns. *Journal of Nursing Education* 47 (6), 260-268.

Magnan MA, Reynolds K (2006) Barriers to addressing patient sexuality concerns across five areas of specialization. *Clinical Nurse Specialist*, 20 (6), 285-292.

Magnan MA, Reynolds KE, Galvin EA (2005) Barriers to addressing patient sexuality in nursing practice. *Medsurg Nursing,* 14 (5), 282-289.

Mercadante S, Vitrano V, Catania V (2010) Sexual issues in early and late stage cancer: a review. *Support Care in Cancer*, 18 (6), 659-665.

Molassiotis A, Chan CWH, Yam BMC, Chan SJ (2000) Quality of life in Chinese women with gynecologic cancers. *Support Care in Cancer*, 8 (5), 414-422.

Molassiotis A, Chan CWH, Yam BMC, Chan SJ, Lam CSW (2002) Life after cancer: adaption issues faced by Chinese gynecological cancer survivors in Hong Kong. *Psycho-Oncology,* 11 (2), 114-123.

Morse JM, Field PA (1996) *Nursing Research: the Application of Qualitative Approaches* (2nd ed.). London: Chapman & Hall.

Morse J, Niehaus L (2007) Combining qualitative and quantitative methods for mixed methods design. In P. Munhall (Ed.), *Nursing Research: A qualitative perspective* (4th ed., pp. 541 – 554). Sudbury: Jones and Bartlett Publishers.

Nakopoulou E, Papaharitou S, Hatzichristou D (2009) Patients' sexual health: a qualitative research approach on Greek nurses' perceptions. *Journal of Sexual Medicine,* 6 (8), 2124-2132.

Odey K (2009) Legitimizing patients sexuality and sexual health to provide holistic care. *Gastrointestinal Nursing,* **7** (8), 43-47.

Padilla GV, Kagawa-Singer M (2003) Quality of life and culture. In C.R. King, & P.S. Hinds (Eds.) *Quality of Life: From Nursing and Patients Perspectives.* (2nd Ed., pp 117-142). Sudbury: Jones and Bartlett Publishers.

Park ER, Norris RL, Bober SL (2009) Sexual health communication during cancer care: barriers and recommendations. *Cancer,* 15 (1), 74-77.

Parkinson N, Pratt H (2005) Clinical nurse specialists and the psychosexual needs of patients with gynaecological cancer. *Menopause International,* 11 (1): 33-35.

Quinn B (2003) Sexual health in cancer care. *Nursing Times,* 99 (4), 32-34.

Ratner ES, Foran KA, Schwartz PE, Minkin MJ (2010) Sexuality and intimacy after gynecological cancer. *Maturitas,* 66 (1), 23-26.

Reis N, Beji NK, Coskun A (2010) Quality of life and sexual functioning in gynecological cancer patients: results from quantitative and qualitative data. *European Journal of Oncology Nursing,* 14 (2), 137-146.

Reynolds KE, Magnan MA (2005) Nursing attitudes and beliefs toward human sexuality: Collaborative research promoting evidence-based practice. *Clinical Nurse Specialist,* 19 (5), 255-259.

Rice AM (2000a) Sexuality in cancer and palliative care 2: Exploring the issues. *International Journal Palliative Nursing,* 6 (9), 448-453.

Rice AM (2000b) Sexuality in cancer and palliative care 1: Effects of disease and treatment. *International Journal Palliative Nursing,* 6 (8), 392-397.

Rosen R, Brown C, Heiman, J, Leiblum S, Meston, C, Shabsigh R, et al. (2000) The Female Sexual Function Index (FSFI): a multidimensional self-report instrument for the assessment of female sexual function. *Journal of Sex Marital Therapy,* 26 (2), 191-208.

Salander P (2002) Bad news from the patient's perspective: An analysis of the written narratives of newly diagnosed cancer patients. *Social Science Medicine,* 55 (5), 721-732.

Saunamaki N, Andersson M, Engstrom M (2010) Discussing sexuality with patients: nurses' attitudes and beliefs. *Journal of Advanced Nursing,* 66 (6), 1308-1316.

Schroder M, Mell LK, Hurteau JA, Collins YC, Rotmensch J, Waggoner SE et al. (2005) Clitoral therapy device for treatment of sexual dysfunction in irradiated cervical cancer patients. *International Journal Radiation Oncology Biology Physics,* 61 (4), 1078-1086.

Spector RE (2004) *Cultural Diversity in Health and Illness* (6th ed.). New York: Prentice Hall Health.

Speziale HJ, Carpenter DR (2007) *Qualitative Research in Nursing: Advancing the Humanistic Imperative* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.

Southard NZ, Keller J (2009) The importance of assessing sexuality: A patient perspective. *Clinical Journal of Oncology Nursing,* 13 (2), 213-217.

Stead ML, Brown JM, Fallowfield L, Selby P (2003) Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer,* 88 (5), 666-671.

Stead ML, Fallowfield L, Selby P, Brown JM (2007) Psychosexual function and impact of gynecologic cancer. *Best Practice & Research Clinical Obstetrics and Gynaecology,* 21 (2), 309-320.

Stilos K, Doyle C, Daines P (2008) Addressing the sexual health needs of patients with gynecologic cancers. *Clinical Journal of Oncology Nursing,* 12 (3), 457-463.

Sunquist K, Yee L (2003) Sexuality and body image after cancer. *Australian Family Physician,* 32 (1/2), 19-22.

Szalai A (1980) The meaning of comparative research on the quality of life. In A. Szalai, & F.M. Andrews (Eds.) *The Quality of Life, Comparative studies.* London: Sage.

Tabachnik BG, Fidell LS (2007) *Using multivariate statistics* (5th ed.). Boston: Pearson.

Tabano M, Condosta D, Coons M (2002) Symptoms affecting quality of life in women with gynecologic cancer. *Seminars in Oncology Nursing,* 18 (3), 223-230.

Tang CSK, Siu BN, Lai FDM, Chung TKH (1996) Heterosexual Chinese women's sexual adjustment after gynecologic cancer. *Journal of Sex Research,* 33 (3), 189-195.

Thirlaway K, Fallowfield L, Cuzick J (1996) The Sexual Activity Questionnaire: A measure of women's sexual functioning. *Quality of Life Research,* 5 (1), 81-90.

Thorne SE (1997) Phenomenological positivism and other problematic trends in health science research. *Qualitative Health Research,* 7, 287-293.

Tsai YF (2004) Nurses' facilitators and barriers for taking a sexual history in Taiwan. *Applied Nursing Research,* 17 (4), 257-264.

Tsimtsiou Z, Hatzimouratidis K, Nakopoulou E, Kyrana E, Salpigidis G, Hatzichristou D (2006) Predictors of physicians' involvement in addressing sexual health issues. *The Journal of Sexual Medicine,* 3 (4), 583-588.

Victorson D, Cella D, Wagner L, Kramer L, Smith ML (2007) Measuring quality of life in cancer survivors. In M. Feuerstein (Ed.) *Handbook of Cancer Survivorship*. (pp79-110). New York: Springer.

Vistad I, Fossa° SD, Dahl AA (2006) A critical review of patient-rated quality of life studies of long-term survivors of cervical cancer. *Gynecologic Oncology,* 102 (3), 563-572.

Wan CH, Yang Z, Meng Q, Feng C, Wang H, Tang X, et al. (2008) Developing and validation of the general module of the system of quality of life instruments for cancer patients. *International Journal of Cancer,* 122 (1), 190-196.

Wenzel LB, Donnelly JP, Fowler JM, Habbal R, Taylor TH, Aziz N, Cella D (2002) Resilience, reflection, and residual stress in ovarian cancer survivorship: a gynecologic oncology group study. *Psycho-Oncology,* 11 (2), 142-153.

White ID (2008) The assessment and management of sexual difficulties after treatment of cervical and endometrial malignancies. *Clinical Oncology,* 20: 488-496.

Wilmoth MC (2006) Life after cancer: what does sexuality have to do with it? *Oncology Nursing Forum,* 33 (5), 905-910.

Wolff SN (2007) The burden of cancer survivorship: A pandemic of treatment success. In M. Feuerstein (Ed.) *Handbook of Cancer Survivorship*. (pp7-18). New York: Springer.

Woo JST, Brotto LA, Gorzalka BB (2009) The role of sexuality in cervical cancer screening among Chinese women. *Health Psychology,* 28 (5), 598-604.

World Health Organization (WHO) QoL Group (1996) What quality of life? The World Health Organization Quality of Life Assessment. *World Health Forum*, 17, 354-356.

Yang K, Yin TJC (1999) Defining the content domain of health-related quality of life for terminally ill cancer patients. *Nursing Research,* 7, 129-144. [in Chinese]

Yin XH, Zhou BB, Zhu CP (2004) The impact factors and interventions on quality of life among cervical cancer patients. *Medical Journal of CASC*, 6 (3), 78-79. [in Chinese]

Zeng JP (2004) Three ethical inequalities of sex purpose and sex morals. *Medicine and Philosophy,* 25 (9), 63-65. [in Chinese]

Zeng YC, Ching SY, Loke AY (2010a) Quality of life measurement in women with cervical cancer: implications for Chinese cervical cancer survivors. *Health and Quality of Life Outcomes,* 8, 30. Available from: http://www.hqlo.com/content/8/1/30.

Zeng YC, Li DM, Loke AL. Life after cervical cancer: quality of life among Chinese women. *Nursing and Health Science,* (under review-a)

Zeng YC, Li QP, Wang N, Ching SSY, Loke AY (2010b) Chinese nurses' attitudes and beliefs toward sexuality care in cancer patients. *Cancer Nursing*, in press.

Zeng YC, Li QP, Li XF, Loke AY. Sexuality concerns among Chinese women after gynecologic cancer. *The Journal of Sexual Medicine*, (under review-b)

Zeng YC, Liu XY, Loke AY (2011) Addressing sexuality concerns of women with gynecologic cancer: Chinese nurses' attitudes and practice. *Journal of Advanced Nursing*, in press.

Zhang XQ, Wan, CH, Lu YB, Yang HY, Luo JH, Huang Y, Meng Q (2009) Development and evaluation of quality of life instruments for cancer patients-Cervix Cancer (QLICP-CE). *China Oncology*, 18 (3), 183-186. [in Chinese]

Appendices

Appendix 1 - 访谈问题纲要

1. 请用你自己的话表述你对**"生活质量"**的定义？
2. 请你列出诊断为宫颈癌后对您的生活质量造成哪些方面的影响？
   - 你躯体健康状况如何？（*如食欲、睡眠、日常生活功能状况，以及有哪些治疗的副作用或后遗症*）
   - 你的心理健康状况如何？（*是否经常感到焦虑、抑郁、或放松、开心，对现在的生活感到满意或对疾病的不缺性感到担忧*）
   - 你的整个社会功能状况如何？（*你现在的社会角色、家庭角色以及人际关系的胜任情况*）
   - 你的精神健康状况如何？（*与患病前比较，你的人生观或对生活的态度有无改变，是否更加珍惜现在的生活，与疾病抗争中，什么样的信念或精神力量帮你应对疾病*）

   （如果你现在有丈夫或男性伴侣，请你回答下面这个问题：）
   - 你与你丈夫或男朋友的亲密关系如何？(*与你治疗前相比，你性生活的次数和质量有无改变*?)

Appendix 2 - The Question Guide

1. In your words, what does quality of life means?
2. How do you perceive the impact of cervical cancer on your quality of life?
   - What do you think about your physical health? *(e.g. your appetite, sleep, daily life functions, treatment side-effects)*
   - What do you think about your psychological health? (*whether always having these moods such as anxiety, depression, feeling satisfied, relaxed or happy with life, worrying about uncertainty of your disease*)
   - What do you think about social function? (*such as your social and family roles and interpersonal relationships*)
   - What do you think about your spiritual health? (*any change in your outlook of life, appreciation your life or others, what beliefs helps you to struggle with your cancer/survivorship)*

   (Please you answer the last question if you have a husband/ male partner)
   - What do you think about your intimate relationship with your husband? (*Compared with pre-treatment, there is any change in the frequency and quality of sexual life?*)

Appendix 3 - The Measurement tool for patients

一般基本情况问卷

编号:_____

尊敬的病友:

您好!我是香港理工大学护理学院的研究生.首先感谢您在百忙之中参与此问卷调查.

为了解妇科癌症患者的生存质量,并探讨其相关影响因素,从而为下一步制订改善您的生存质量和满足您的健康照顾需求的干预措施提供客观依据,请您协助我们完成以下相关问卷.此问卷共 3 面，约需 20 分钟.

此问卷不记名,仅供统计用.请您如实地填答,不要有任何顾虑.再次感谢您的真诚合作!

（您的基本情况:请您在下列符合您情况的选项前的空格内打 [√]或在横线上填写.）

1.**年龄**:□(1)20 岁及以下; □(2)20-29 岁; □(3)30-39 岁;

□(4)40-49 岁; □(5)50 岁及以上

2.**文化程度**: □(1)初中以下; □(2)初中; □(3)高中; □(4)中专;

□(5)大专; □(5)大学本科及以上

3.**就业状态**: □(1)在职; □(2)离职或失业(在诊断前);

□(3) 离职或失业(在诊断后); □(4)退休

4.**婚姻状况**: □(1)未婚;□(2)已婚; □(3)离异(在诊断前);

□(4) 离异(在诊断后);□(5)其它

5.**子女状况**: □(1)无; □(2)有

6.**您疾病的诊断名称**:_____

7.**初次诊断的日期**:_____(年/月/日)

8.**疾病的分期**：□(1)早期; □(2)中期; □(3)晚期

9.**治疗方式**：□(1)单纯手术; □(2)单纯放疗; □(3)手术加放疗;

□(4) 放疗加手术; □(5)手术加放疗和化疗

10. **治疗期间谁提供主要照顾**（不包括医护人员）:_____（与您的关系）

性健康问卷

（性是人的基本生理需要，性健康是个人整体健康和生活质量的重要组成部分。妇科癌症患者的性健康可能经历某些方面的改变,以下问题是反映这种改变。）

第一部分 请您仔细阅读以下问题，选出最能反应您目前性健康状况的选项

与**自身形象**相关的条目					
在过去1个月内		很同意	同意	不同意	很不同意
1.	您不喜欢您的外表	□	□	□	□
2.	您喜欢您目前的外表	□	□	□	□
3.	许多人觉得您的外表好看	□	□	□	□
4.	您生理上缺乏吸引力	□	□	□	□
5.	您的身体看起来性感	□	□	□	□
与**角色和人际关系**有关的条目					
在过去1个月内		非常	一般	一点	一点也不
6.	疾病影响到您自身作为女人的感觉吗？	□	□	□	□
7.	手术治疗后，您丈夫/性伴侣觉得您仍是完整的女人吗？	□	□	□	□
8.	疾病影响到您作为妻子的角色吗？	□	□	□	□
9.	疾病影响到您作为母亲的角色吗？	□	□	□	□
10.	疾病影响到您和您丈夫/性伴侣整体的性关系吗？	□	□	□	□
与**性行为**（包括亲吻、拥抱、抚摸以及性交的任何亲密性行为）相关的条目					
在过去1个月内		非常	一般	一点	一点也不
11.	性行为在您的生活中重要吗？	□	□	□	□
12.	您与您丈夫/性伴侣有亲密性行为？	□	□	□	□
13.	您这个月内享受性行为吗？	□	□	□	□
14.	您这个月性交的频率？	□	□	□	□
		4次以上	3-4 次	1-2次	1次也没有
15.	您对这个月性交的频率感到满意吗？	□	□	□	□
		非常满意	满意	不满意	非常不满意
与**性功能**相关的条目					
在过去1个月内		非常	一般	一点	一点也不
16.	您对您丈夫/性伴侣整体的性功能感到担忧吗？	□	□	□	□
17.	您对您自己整体的性功能担忧吗？	□	□	□	□
18.	您这个月有过性生活的欲望吗？	□	□	□	□
19.	在性生活时，您这个月注意到阴道干涩的情况频繁吗？	□	□	□	□
20.	在性交过程中，您这个月感到阴道疼痛或不舒适吗？	□	□	□	□
21.	在性交过程中，您这个月有过阴道出血吗？	□	□	□	□

22.	在性交过程中，您因为阴道太小而使您性交时感到烦恼吗？	□	□	□	□
23.	您这个月能完成性交吗？	□	□	□	□
24.	性交中，您能达到性高潮吗？	□	□	□	□
25.	性生活后，您觉得愉悦吗？	□	□	□	□
附加条目（有关您性健康负面改变的程度）					
与诊断妇科癌症前相比较：		非常大	一般	一点	没有变化
26.	您对性生活的兴趣有改变吗？	□	□	□	□
27.	您过性生活的频率有改变吗？	□	□	□	□
28.	您性交的方式有变化吗？	□	□	□	□
29.	您阴道干涩的情况有变化吗？	□	□	□	□
30.	您感到您阴道的大小有变化吗？	□	□	□	□
31.	您性交时疼痛的经历有变化吗？	□	□	□	□
32.	您与您丈夫性关系的质量有改变吗？	□	□	□	□

第二部分：如果您目前无性行为，请从下面的选项中选出其原因。

目前，您没有性生活的原因是： （根据您的实际情况，您可选择多项）		
1.	您没有丈夫/性伴侣	□
2.	您太疲劳(可能由于疾病或治疗如放疗、化疗所引起)	□
3.	您的丈夫/性伴侣太疲劳	□
4.	您对性没有兴趣（可能归因为治疗的副作用）	□
5.	您的丈夫/性伴侣对性没有兴趣	□
6.	您丈夫/性伴侣没有主动要求过性生活	□
7.	您有生理上的问题（如性交疼痛）让性关系变得困难或不舒适	□
8.	您的丈夫/性伴侣健康上有问题让性关系变得困难或不舒适	□
9.	您的年纪偏大而缺乏过性生活的体力和精力	□
10.	您害怕性生活会影响治疗效果	□
11.	您担心性生活会负面地影响您疾病的康复	□
12.	您担心癌症可通过性交传播给您丈夫/性伴侣	□
13.	您丈夫/性伴侣担心癌症可通过性交传播	□
14.	您担心治疗后过性生活会导致癌症的复发	□
15.	没有明确的原因	□

再次感谢您的帮助，您提供的信息将会为您绝对保密！

Appendix 4 - The English translations of the sexuality scale for women with gynecologic cancer

(Sex is one of basic needs of human beings. Sexual health is an important part of overall health and quality of life. Women with gynecologic cancer may experience certain changes in their sexuality. The following questions can reflect all these possible changes)

Part 1 Please read each of the following questions in detail. Pick the option which most represents your feeling and experience about your sexual health in the past month.

Body image					
During the past month		Definitely agree	Agree	Disagree	Definitely disagree
1.	You dislike your appearance	□	□	□	□
2.	You like your looks just the way they are	□	□	□	□
3.	Most people would consider you good-looking	□	□	□	□
4.	You are physically unattractive	□	□	□	□
5.	Your body is sexually appearing	□	□	□	□
Role and relationship issues					
During the past month		Very	Average	A bit	Not at all
6.	Has cancer affected your sense of femininity?	□	□	□	□
7.	After cancer treatment, has cancer affected the way your husband/intimate partner feeling about you as a woman?	□	□	□	□
8.	Has cancer affected you role as wife/sexual partners?	□	□	□	□
9.	Has cancer affected your role as a mother?	□	□	□	□
10.	Has cancer affected your overall sexual relationship with your husband/intimate partner?	□	□	□	□
Sexual activity (not limited sexual intercourse and including any intimate activities (e.g. holding hands, kiss, embrace and touching) in a sexual nature not affection nature					
During the past month		Very	Average	A bit	Not at all
11.	Was 'having sex' an important part of your life?	□	□	□	□
12.	Have you had intimate activity this month?	□	□	□	□
13.	Did you enjoy sexual activity this month?	□	□	□	□
14.	How frequent did you have sexual intercourse for this month?	□	□	□	□
		5 times or more	3 – 4 times	1 – 2 times	Not even once
15.	Are you satisfied with the frequency of sexual intercourse in this month?	□	□	□	□
		Very	Average	A bit	Not at all
Sexual function					
During the past month		Very	Average	A bit	Not at all
16.	Are you worried about your husband/intimate partners' sexual function?	□	□	□	□
17.	Are you worried about your own sexual function?	□	□	□	□

18.	Did you have sexual desire in this month?	□	□	□	□
19.	Did you feel the dryness of your vagina during intercourse?	□	□	□	□
20.	Have you had any pain or discomfort during sexual intercourse?	□	□	□	□
21.	Have you experience bleeding during intercourse?	□	□	□	□
22.	Did you feel that intercourse was bothersome because your vagina felt too small?	□	□	□	□
23.	Were you able to complete sexual intercourse?	□	□	□	□
24.	Have you reached orgasm?	□	□	□	□
25.	Did you feel satisfied after having sex?	□	□	□	□
Additional items (the degree of negative changes of your sexuality)					
Compared to before you were diagnosed with gynecologic cancer		Big changes	Some changes	Little changes	No changes
26.	Has your interest in sexual activity changed?	□	□	□	□
27.	Has your frequency of your sexual activity changed?	□	□	□	□
28.	Has your preference to types of sexual activity changed?	□	□	□	□
29.	Has the dryness of your vagina changed?	□	□	□	□
30.	Do you feel that the size of your vagina changed?	□	□	□	□
31.	Has the pain you experience during sexual intercourse changed?	□	□	□	□
32.	Has the quality of your sexual relationships changed?	□	□	□	□

Part 2: If you have no sexual activity currently, please provide relevant reasons.

You am not sexually active at the moment because: (please tick as many of these items as apply)		
1.	You do not have husband/intimate partner	□
2.	You are too tired (possibly due to cancer or treatment such as radiation therapy of chemotherapy)	□
3.	Your husband/intimate partner is too tired	□
4.	You am not interested in sex (possibly due to side-effects of cancer treatment)	□
5.	Your husband/intimate partner is not interested in sex	□
6.	Your husband/intimate partner did not initiate sexual activity	□
7.	You have a physical problem (e.g. dyspareunia) which makes sexual relations difficult or uncomfortable	□
8.	Your husband/intimate partner has poor health conditions which make sexual relations difficult	□
9.	You feel lack of energy to engage in sexual activity due to aging problems	□
10.	You fear that sex weakens the potency of therapeutic drugs and treatment	□
11.	You worry about sexual intercourse influence disease recovery	□

12.	You worry that cancer may be transmitted through sexual activity to your husband/intimate partner	□
13.	Your husband/intimate partner worry that cancer can be transmitted through sexual activity	□
14.	You fear that cancer will worsen if continuing to have sex after treatment	□
15.	You fear sexual activity because of just finishing initial cancer treatment	□

Thanks for your help, all information you provided will keep strictly confidential!

Appendix 5 - The Measurement tool for nurses (Chinese version)

尊敬的护士同仁: 您好!

我是香港理工大学护理学院的研究生。首先感谢您在百忙之中参与此项调查。为提供高质量的整体护理，需要了解病人全身心的健康需求。本研究想了解护士对病人的敏感健康问题的态度、信念、实践以及影响因素。请您协助我完成以下相关问卷。此问卷调查不记名,仅供统计用。请您如实地填答,不要有任何顾虑.您填写的信息会为您绝对保密。此问卷共4面，约需要20分钟。

第一部分：个人的基本信息

请您在下列符合您情况的选项前的空格内打[√]或在横线上填写. 不记名, 仅供统计用, 请您如实地填答, 不要有任何顾虑.

1. 年龄: □(1)≤20 岁; □(2)21-30 岁; □(3)31-40 岁;
□(4)41-50 岁; □(5)>50 岁
2. 工龄: □(1)<1 年; □(2)1-5 年; □(3)6-10 年;
□(4)11-20 年; □(5)>20 年
3. 职称: □(1)士级; □(2)初级; □(3)中级; □(4)高级;
4. 文化程度: □(1)中专; □(2)大专; □(3)本科; □(4)硕士
5. 婚姻状况: □(1)未婚; □(2)已婚;
6. 所在的医院: _____

第二部分：对病人性健康问题的态度和信念

以下观点有 6 个数字，请圈出最合适的数字并能代表你对每个观点的程度：从“很不赞同”→“很赞同”	很不赞同					很赞同
1. 谈论病人与性有关的问题对病人的健康结局很重要	1	2	3	4	5	6
2. 我懂得疾病和治疗如何影响病人的性	1	2	3	4	5	6
3. 谈论性有关的话题会让我感到不舒服	1	2	3	4	5	6
4. 与我同事相比，我感到相对舒适地与病人谈论性有关的话题	1	2	3	4	5	6
5. 许多住院病人因为太虚弱而对性没有兴趣	1	2	3	4	5	6
6. 我会花时间去与病人谈论她们与性有关的忧虑	1	2	3	4	5	6
7. 无论何时，病人问我与性有关的问题，我都建议她们去找医生讨论	1	2	3	4	5	6
8. 我对自己解决病人与性有关忧虑的能力有信心	1	2	3	4	5	6

9. 与病人谈论性是非常隐私的话题	1	2	3	4	5	6
10. 给病人机会去表达她们与性有关的忧虑是护士的责任	1	2	3	4	5	6
11. 只有在病人主动提出时才去谈论性	1	2	3	4	5	6
12. 病人期望护士询问她们与性有关的忧虑	1	2	3	4	5	6

第三部分：对病人性健康问题的护理实践

以下观点有 6 个数字，请圈出最合适的数字并能代表你对每个观点的程度：从“从没”→“经常”

从没 ... 经常

在过去 1 个月内，您是否经常

13. 评估病人的性健康	1	2	3	4	5	6
14. 倾听病人的性忧虑	1	2	3	4	5	6
15. 询问与病人性健康相关的问题	1	2	3	4	5	6
16. 询问病人因疾病而导致性或婚姻关系危机	1	2	3	4	5	6
17. 告知病人癌症对性功能的影响	1	2	3	4	5	6
18. 讨论病人的性忧虑	1	2	3	4	5	6
19. 向病人讲述癌症相关的治疗对性造成的副作用	1	2	3	4	5	6
20. 向病人提供性健康教育的知识和信息	1	2	3	4	5	6
21. 与育龄期病人讨论相关治疗造成妇女提前绝经的风险	1	2	3	4	5	6
22. 与病人讨论因自身形象的改变而对性的影响	1	2	3	4	5	6

第四部分：促进护士对病人性健康问题护理实践的因素

以下观点有 6 个数字，请圈出最合适的数字并能代表你对每个观点的程度：从“很不赞同”→“很赞同”

很不赞同 ... 很赞同

在过去 1 个月内，您是否经常

23. 想了解病人的性健康史与其疾病的关系	1	2	3	4	5	6
24. 病人主动向医护人员倾诉其性健康问题	1	2	3	4	5	6
25. 护士具备良好的交流技巧	1	2	3	4	5	6
26. 护士具备扎实的性健康理论知识基础	1	2	3	4	5	6
27. 与病人有良好的护患关系	1	2	3	4	5	6

28. 有比较隐私的环境去评估病人的性健康和向病人提供性咨询服务	1	2	3	4	5	6
29. 把评估病人性健康纳入日常护理实践	1	2	3	4	5	6
30. 为护士提供与病人的性健康评估和咨询的培训	1	2	3	4	5	6

第五部分：阻碍护士对病人性健康问题护理实践的因素

以下观点有 6 个数字，请圈出最合适的数字并能代表你对每个观点的程度：从“很不赞同”→“很赞同”	很不赞同					很赞同
与护士有关的因素						
31. 感到尴尬	1	2	3	4	5	6
32. 自身知识有限	1	2	3	4	5	6
33. 缺乏相关经验	1	2	3	4	5	6
34. 害怕侵犯病人隐私	1	2	3	4	5	6
35. 没有接受过相关培训	1	2	3	4	5	6
与病人有关的因素						
36. 病人感到尴尬	1	2	3	4	5	6
37. 病人感到护士对性健康的评估与治疗无关而不愿意配合	1	2	3	4	5	6
38. 病人故意掩盖与性健康相关的信息	1	2	3	4	5	6
39. 病人文化程度低而不知怎样回答护士的问题	1	2	3	4	5	6
40. 病人拒绝讨论性健康	1	2	3	4	5	6
工作环境的局限						
41. 评估病人性健康不是日常护理工作常规	1	2	3	4	5	6
42. 在同事中没有榜样去学习了解如何为病人提供性健康咨询	1	2	3	4	5	6
43. 缺乏隐私的环境去评估病人性健康	1	2	3	4	5	6
44. 资源有限	1	2	3	4	5	6
45. 由于护士编排不够，导致护士的时间和精力有限	1	2	3	4	5	6
因为一些与癌症和性有关的陈见						
46. 癌症病人要考虑比性更重要的事情	1	2	3	4	5	6
47. 在癌症的诊断和治疗中，性是病人次优的健康需要	1	2	3	4	5	6

48. 癌症是可以通过性传播给配偶	1	2	3	4	5	6
49. 性生活会影响药物的疗效以及其它治疗	1	2	3	4	5	6
50. 治疗后过性生活会导致癌症复发	1	2	3	4	5	6

再次感谢您的真诚合作!

Appendix 6 - The measurement tool for nurses (English translation)

Part 1Demographic Sheet

1. Age
2. Years of nursing work
3. Work position
4. Education levels
5. Marital status
6. Hospital types

Part 2 Sexuality Attitudes and Beliefs Survey

1. Discussing sexuality is essential to patient's health outcomes
2. I understand how my patient's disease and treatment might affect their sexuality
3. I am uncomfortable talking about sexual issues
4. I am more comfortable talking about sexual issues with my patients than are most of the nurses I work with
5. Most hospitalized patients are too sick to be interested in sexuality
6. I make time to discuss sexual concerns with my patients
7. Whenever patients ask me a sexual related question, I advise them to discuss the matter with their physician
8. I feel confident in my ability to address patient's sexual concern
9. Sexuality is too private an issue to discuss with patients
10. Giving a patient permission to talk about sexual concerns is a nursing responsibility
11. Sexuality should be discussed only if initiated by the patients
12. Patients expect nurses to ask about their sexual concerns

Part 3 The Inventory of sexuality care in nursing practice

During your daily nursing practice, in the past month how often you

13. provided sexuality assessment
14. asked the patients about problems in sexual functioning
15. listened to patient's concern about sexuality
16. asked the patients about possible problems in their sexual relationships
17. answered patient's questions about sexuality
18. told the patient about possible effects of cancer on sexual functioning on my initiative
19. told the patients about the possible side-effects of cancer treatment on sexuality
20. discussed patients' concerns of the body image changes and their effects on sexuality
21. discussed with the patients who are in fertility ages about the early risk of menopause risk
22. provided information/ education regarding patients' sexuality concern

Part 4 The Inventory of nurses perceived facilitators relating to sexuality care in nursing practice

23. Want to know if patients' sexual history is related to their disease
24. Patients initiatively expressed that they have sexual problems
25. Nurses with good communication skills
26. Nurses with sound theoretical knowledge base about sexuality
27. Having a good nurse-patient relationship

28. Having a private environment
29. After taking a sexual history was added into the nursing practice
30. Providing relevant training about how to assess patients' sexual health and how to provide sexual counseling for patients

Part 5 The Inventory of Barriers relating to sexuality care in nursing practice

Due to nurses' factors

31. Feeling embarrassed taking a sexual history
32. Limited knowledge
33. Lack of relevant experience
34. Afraid of violating patients' privacy
35. Inadequate education preparation

Due to patients' factors

36. Patients feel embarrassed
37. Patients don't want to talk because they feel it isn't relevant to their treatment
38. Patients purposefully conceal information
39. Patients' education levels are too low to know how to answer nurses' questions
40. Patients refusal

Due to organization restriction

41. Assessing sexuality is not part of the nursing routine
42. Lack of a role model to learn how to discuss sexual issues with patients
43. Lack of private setting to take a sexual history
44. Limited resources
45. Staff shortages, energy and time

Due to myths about sexuality

46. People with cancer have more things to be concerned about than having sex
47. Sexuality represents a low priority issues at diagnosis and during treatment of cancer
48. Cancer is contagious and may be transmitted through sexual activity to partners
49. Sex weakens the potency of therapeutic drugs and treatment such as radiation therapy
50. Cancer will recur if continuing to have sex after treatment

Thank you for your help!

Appendix 7 - 有关资料
(宫颈癌康复者的生存质量研究)

诚邀阁下参加由**袁桢德**教授负责督导, 由**曾迎春**小姐负责执行的研究计划。她是香港大学护理学院学生。

这项研究的目的是探讨宫颈癌康复者的生存质量, 本研究采用质性研究的途径：书信访谈。参与者们可在无时间限制的情况下表述你们在康复期内的生活质量。

虽然此次访谈不会给您带来任何直接的好处，但您提供有关您的生活质量的相关信息将会帮助健康照顾者制定相应的干预措施：如何提高您和其他宫颈癌康复者的生活质量以及如何更好地满足您的健康照顾需求。此访谈无明显潜在不适。但有可能在书信访谈的过程让您回忆起过去有关疾病的不愉快体验。

阁下享有充分的权利在研究开始之前或之后决定退出这项研究,而不会受到任何对阁下不正常的待遇或被追究责任。凡有关阁下的资料将会保密,一切资料 的编码只有研究人员得悉。

如果阁下对这项研究有任何的不满,可随时与香港理工大学人事伦理委员会 秘书吕小姐联络 (地 址 : 香 港 理 工 大 学 研 究 事 务 处 M502 室 转交)。

如果阁下想获得更多有关这项研究的资料, 请与**曾迎春**小姐联络,电话 3400 8190 或联络她的导师**袁桢德**教授,电话分别为 2766 6386.

谢谢阁下有兴趣参与这项研究。

研究员：

_____ _____

袁桢德教授 曾迎春

Appendix 8 - Information Sheet

Title: Quality of life among Chinese cervical cancer survivors

You are invited to participate in a study supervised by **Prof. Alice Yuen Loke**, and conducted by **Miss Ying Chun Zeng**, who is a student of the School of Nursing in the Hong Kong Polytechnic University.

The purposes of this study are to explore the quality of life among Chinese cervical cancer survivors, and to generate the findings for the construction of a quality of life scale appropriate to Chinese cervical cancer survivors. A qualitative methodology will be adopted. The interview method would adopt written response interview. There is no time limit for written response interview.

Despite in the process of acting as a participant, there are no direct benefits to you. However, your perceptions of your quality of life will guide healthcare providers to develop relevant interventions about how to improve your and other cervical cancer survivors' quality of life and healthcare needs. Acting as participants, there are no obvious risks. One possible risk is that during the process of written response interview, it may remind your disease experience causing some potential uncomfortable feeling.

You have every right to withdraw from the study before or during the measurement without penalty of any kind. All information related to you will remain confidential, and will be identifiable by codes known to the researchers.

If you have any complaints about the conduct of this research study, please do not hesitate to contact **Ms. Kath Lui**, Secretary of the Human Subjects of Ethics Sub-committee of the Hong Kong Polytechnic University in person or in writing (c/o Research Office in Room M502 of the University).

If you would like more information about this study, please contact **Ying Chun Zeng** at telephone number 3400 8190, or her supervisor **Prof. Alice Yuen Loke** by 2766 6386.

Thank you for your interest in participating in this study.

Investigators:

_____ _____

Prof Alice Loke Ying Chun Zeng

Appendix 9 - 有关资料
(关注妇科癌症康复者的性健康)

诚邀阁下参加由**袁桢德**教授负责督导, 由**曾迎春**小姐负责执行的研究计划。她是香港大学护理学院学生。

这项研究的目的是探讨关注妇科癌症康复者的性健康。 本研究采用量性研究通过横断面的问卷调查。此调查采用参与者自我填写的方式，此访问卷大约需要的时间约 20 分钟。

虽然此次访谈不会给您带来任何直接的好处，但您提供的相关信息将会帮助健康照顾者制定相应的干预措施：如何提高您和其他妇科癌康复者的性健康和生活质量以及如何更好地满足您的健康照顾需求。此问卷调查无明显潜在不适。

阁下享有充分的权利在研究开始之前或之后决定退出这项研究,而不会受到任何对阁下不正常的待遇或被追究责任。凡有关阁下的资料将会保密,一切资料 的编码只有研究人员得悉。

如果阁下对这项研究有任何的不满,可随时与香港理工大学人事伦理委员会 秘书吕小姐联络 (地 址 : 香 港 理 工 大 学 研 究 事 务 处 M502 室 转交)。

如果阁下想获得更多有关这项研究的资料, 请与**曾迎春**小姐联络,电话 3400 8190 或联络她的导师**袁桢德**教授,电话分别为 2766 6386.

谢谢阁下有兴趣参与这项研究。

研究员：

_____ _____

袁桢德教授 曾迎春

Appendix 10 - Information Sheet

Title: **Sexuality concerns of women with gynecologic cancer from both patient and nurse perspectives**

You are invited to participate in a study supervised by **Prof. Alice Yuen Loke**, and conducted by **Miss Ying Chun Zeng**, who is a student of the School of Nursing in the Hong Kong Polytechnic University.

The purposes of this study are to are to investigate the impact of gynecological cancer and related treatment on women's sexuality, to describe Chinese nurses' attitudes and beliefs with regard to discussing sexuality concerns with gynecological cancer patients, to investigate their current practice in addressing gynecological cancer patients' sexuality concerns, and to explore the possible facilitators or barriers influencing these Chinese nurses' practice. A quantitative methodology will be adopted by self-reported questionnaires. Time requirement needs around 20 minutes.

In the process of acting as a participant, there are no direct benefits and no obvious risks to you. Your perceptions of addressing gynecologic cancer patients' sexuality concerns will guide healthcare providers to develop relevant interventions, which will improve the quality of holistic care and achieve better patient outcomes.

You have every right to withdraw from the study before or during the measurement without penalty of any kind. All information related to you will remain confidential, and will be identifiable by codes known to the researchers.

If you have any complaints about the conduct of this research study, please do not hesitate to contact **Ms. Kath Lui**, Secretary of the Human Subjects of Ethics Sub-committee of the Hong Kong Polytechnic University in person or in writing (c/o Research Office in Room M502 of the University).

If you would like more information about this study, please contact **Ying Chun Zeng** at telephone number 3400 8190, or her supervisor **Prof. Alice Yuen Loke** by 27666386.

Thank you for your interest in participating in this study.

Investigators:

_____	_____
Prof Alice Loke	Ying Chun Zeng

Appendix 11 - 参与研究同意书

宫颈癌康复者的生存质量研究

本人，_____（姓名），现同意参与由**袁桢德**教授督导，**曾迎春**小姐负责进行的“宫颈癌康复者的生存质量研究”。

本人知悉此研究所得的资料可能被用作日后的研究及发表，但本人的私隐权利将得以保留，即本人的个人数据不会被公开。

研究人员已向本人清楚解释列在所附数据卡上的研究程序，本人明了当中涉及的利益及风险；本人自愿参与研究项目。

本人知悉本人有权就程序的任何部分提出疑问，并有权随时取消参与此研究之权利，而不会对本人的治疗有任何影响。

参与者姓名 _____

参与者签署_____

研究人员姓名 _____

研究人员签署 _____

日期 _____

Appendix 12 -Consent to Participate in Research

Quality of Life among Chinese Cervical Cancer Survivors

I _____ , hereby consent to participate in the captioned research supervised by **Prof. Alice Yuen Loke**, conducted by **Miss Ying Chun Zeng**.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e. my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I can keep a copy of this information sheet if I wish. I understand the benefit and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant _____

Signature of participant_____

Name of researcher _____

Signature of researcher _____

Date _____

Appendix 13 - 参与研究同意书

关注妇科癌症康复者的性健康

本人，_____（姓名），现同意参与由**袁桢德**教授督导，**曾迎春**小姐负责进行的"关注妇科癌症康复者的性健康"。

本人知悉此研究所得的资料可能被用作日后的研究及发表，但本人的私隐权利将得以保留，即本人的个人数据不会被公开。

研究人员已向本人清楚解释列在所附数据卡上的研究程序，本人明了当中涉及的利益及风险；本人自愿参与研究项目。

本人知悉本人有权就程序的任何部分提出疑问，并有权随时取消参与此研究之权利，而不会对本人的治疗有任何影响。

参与者姓名 _____

参与者签署_____

研究人员姓名 _____

研究人员签署 _____

日期 _____

Appendix 14 - Consent to Participate in Research
Sexuality concerns of women with gynecologic cancer from both patient and nurse perspectives

I _____ , hereby consent to participate in the captioned research supervised by **Prof. Alice Yuen Loke**, conducted by **Miss Ying Chun Zeng**.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e. my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I can keep a copy of this information sheet if I wish. I understand the benefit and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant _____
Signature of participant_____
Name of researcher _____
Signature of researcher _____
Date _____